

A Guide for People Who Become Deaf or Severely Hard of Hearing

***A Late-Deafened
Consumer's Perspective***

by Karen Rockow, PhD

**Developed under a contract from the
Massachusetts Commission for the Deaf and
Hard of Hearing**

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Preface & Acknowledgements

From the First Edition

From Karen ~

Speak with anyone who has lost his or her hearing after developing spoken language and you will hear a constant refrain:

* If only I had known about the Association of Late-Deafened Adults or Self Help for Hard of Hearing People, If only I'd known where to turn to learn how to speechread or to learn sign language, if only I'd known there was such a thing as CART service . . .

This book has been written as an antidote to the "if onlys". Although I've written it in the last few months, it has been years in the making.

Many individuals contributed to the development of this Guide. Thanks go to the Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH) for heeding the call of late-deafened and severely hard of hearing people. I worked closely with Nan Robbins, former Deputy Commissioner for Policy and Programs, who devoted hours on end to the project and mobilized the resources and staff of the Commission in a way that would be the envy of any five-star general. I'm extremely grateful to John Anderson, Helen Fleming, Annette Posell, and Jane Sokol Shulman, who kindly agreed to share their experiences and Quotable Quotes, and to Nancy Delaney, who shared her ongoing adventure with her cochlear implant. Hartmut Teuber reviewed the section on manual communication; Bev Biderman helped with the section on cochlear implants; Carol Menton offered numerous comments and suggestions; Dan MacDonald took photographs. I also want to thank other consumers who reviewed the outline and offered suggestions; Linda Mazzola, Diana Sprague, and Gerry Lyons.

At the MCDHH, Carole Rossick reviewed all sections for assistive technology terminology; Andrea Galvin assisted with production details, Andrea Koenig with financial assistance information, Liz Banta with information about case management, Brenda Schertz with provision of a vast array of topical information available at the MCDHH Resource Library and Information Service; Brenda Schertz and Jonathan O'Dell took photographs. Geoff Plant, who introduced me to tactile aids in studies in which I was a research subject, read the manuscript, as did his wife Kerry and my "editors on call", Eve Golden and Lee Lockwood. Finally, I want to thank the Ella Lyman Cabot Trust, whose generous grant supporting research for a longer book about hearing loss which I'm still writing, has done double duty by simultaneously furnishing me with pertinent research to bring to this more specialized volume.

Karen Rockow

From MCDHH ~

In our work through the last ten years at the MCDHH, people who have become deaf or severely hard of hearing, nationally and in Massachusetts, have impressed upon us the need for clear information on acquired hearing loss... distinct from information on deafness at birth and in the very early years of life. The information is needed by consumers themselves who have become deaf and by the professionals whom they meet when hearing loss occurs.

In addition to the “if only I had known” refrain from individuals who have become deaf or severely hard of hearing we hear:

- * Too many professionals who are supposed to be able to help late-deafened or very severely hard of hearing people just don’t understand what it really means to **become deaf**. They can’t and don’t give us the information, support, contacts and even appropriate communication access that we need in order to deal with hearing loss. They too often just don’t understand “how it really is” and “what we really need”.

These two refrains, both loud and clear, have resulted in this Guide which will be made available to people who become deaf or severely hard of hearing, the professionals who work with them, and their family, friends and colleagues.

This past year, discussions of the needs of late-deafened people and possible solutions with the MCDHH Late-Deafened Work Group resulted in the MCDHH competitive contract for a writer to develop this Guide. The Work Group members are Arnold Adelman, Matthew Ferrera, Jim Grealish, Carol Lee Hilbinger, Marylyn Howe, Reggie Krystiniak, Betty Lynch, Gerry Lyons, Linda Mazzola, Carol Menton, Jane Sokol Shulman, and Annette Posell. MCDHH is very grateful to the Work Group members and to the many, many other late-deafened, hard of hearing, and “enlightened” hearing professionals each year who share their knowledge and thoughts with us and who come together to assist in creating solutions.

MCDHH Management Team

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Introduction

Acquired deafness impacts every aspect of our lives and it can be devastating. By seriously interfering with spoken communication, it affects our feelings of self, of competence, our family relationships, our careers. It demands that we make major adjustments in our lives, that we reevaluate our very existences and hopes.

This book is intended as an “adjustment manual,” a resource guide for people who have lost all or most of their hearing during their teenage or adult years. It presents information about

- the impact of hearing loss
- available resources and services
- communication options
- assistive technology
- coping strategies
- connecting with other people who have become deaf or severely hard of hearing

In short, this book seeks to help late deafened people learn to become deaf or hard of hearing gracefully.

Some of the issues we touch are emotionally charged and have in the past provoked vehement controversy. I’ve tried to present information in a clear, non-judgmental way so that this book will help people make their own informed decisions. As Donna Sorkin, former Executive Director of Self Help for Hard of Hearing People, recently said, “Information puts people in control.” We hope that the book will also be widely distributed among service providers — audiologists, primary care physicians, and social workers — and will help them to understand and give knowledgeable advice to their deafened clients.

“On July 17, 1986, I became deafened overnight, due to an unknown virus. When I first became deafened, I had never met a deaf person and knew absolutely nothing about deafness.... No one told me how to live with my deafness.... I thought my life was over.”

— Bena Shuster in *Life After Deafness*

How to Use the Guide

You can pick up this guide and start reading at any section that interests you. We've divided the book into eight chapters:

- Chapter 1* deals with the effects of deafness on people's lives. If you're newly deafened, it will tell you what to expect and discuss some of the emotions you may have.
- Chapter 2* lists organizations and agencies that you can turn to for information and support, as well as information about medical procedures.
- Chapter 3* discusses options you may wish to investigate for your communication needs.
- Chapter 4* talks about communication skills.
- Chapter 5* introduces assistive technology that is available for your use.
- Chapter 6* discusses auxiliary services, such as interpreters and CART service, that you may want to use.
- Chapter 7* discusses methods you can use to optimize your communication skills and make life with hearing loss easier.
- Chapter 8* draws on the experiences of many late-deafened adults in dealing with everyday situations. It also deals with your rights under the Americans with Disabilities Act (ADA).

The Finale lists books for further reading and ordering information about pamphlets and books listed in the text.

Remember that it's impossible for a book of this sort to remain completely current for long. The technology is changing rapidly. Organizations, contacts, Web pages, and the like come and go. If you find any of these glitches or think we should include additional information in a subsequent edition or update, please contact me at krockow@compuserve.com or write the Massachusetts Commission for the Deaf and Hard of Hearing at 150 Mt. Vernon Street, Suite 550, Dorchester, MA 02125. We also welcome any other comments.

Terms We'll Use in the Guide

What's the difference between *hard of hearing* and *deaf*? Between *Deaf* (with an uppercase D) and *deaf* (with a lowercase D)? Between *late deafened* and *Deaf*? You can define these terms in many ways. Terminology has sometimes been a source of confusion and even strain among people with hearing loss. "When I use a word, it means just what I choose it to mean," said Humpty Dumpty. Here are the meanings I'll use in this book:

hard of hearing (HoH): Describes people who still have some useful hearing and can understand spoken language through hearing in some situations, with or without amplification. Most HoH people can still use the telephone and make use of hearing aids and assistive devices. The degree of hearing loss can vary considerably, from mild to profound.

deaf: An audiological term used to describe degree of hearing loss. People who are deaf have little or no residual hearing. They may use sign language or assistive devices and speech reading, and hearing aids may help their speech reading. Those who use spoken English as their preferred form of communication are called *oral deaf*.

late-deafened or deafened: Describes people who lost all or most of their hearing during or after the teen years, either suddenly or progressively. Most cannot use the telephone and need sign language or speech reading to understand conversation. Sometimes called *adventitiously deaf*.

Deaf: People who think of themselves as members of the Deaf community, for whom American Sign Language (ASL) is the preferred form of communication. It is a common misconception that all Deaf people have no hearing whatsoever. In reality, the degree of hearing loss varies considerably. It is also a common misconception that Deaf people only relate to other Deaf people and only use ASL. In reality, Deaf people live and interact in the hearing world every day. And many Deaf people are bi- and even trilingual and work and socialize quite comfortably in the hearing world. The common denominator is that most Deaf people lost their hearing before the acquisition of spoken language (they are sometimes said to be “pre-lingually deaf”), and view hearing loss not as a medical condition, but as a cultural distinction. Some late-deafened individuals also involve themselves in the Deaf community, while simultaneously maintaining close ties with hearing friends, family and community.

As we’ll discuss later, many people who think of themselves as late-deafened sometimes introduce themselves as being hard of hearing. And many people with severe to profound hearing losses prefer to call themselves hard of hearing. This book is specifically written for late-deafened individuals, and addresses their specific and urgent problems. At the same time, it should be of interest to others with lesser hearing losses, as well as to hearing friends and caregivers who wish to understand more about the experience of losing one’s hearing after having grown up as a hearing person.

Acronyms We'll Use

ADA	Americans With Disabilities Act
ALD	Assistive Listening Devices and Systems
ASL	American Sign Language
CAN	Computer Aided Notetaking
CART	Communication Access Realtime Translation
CC	closed captions
DAI	Direct Audio Input
DHILS	Independent living services for deaf and hard of hearing people
MCDHH	Massachusetts Commission for the Deaf and Hard of Hearing
MRC	Massachusetts Rehabilitation Service
PSE	Pidgin Sign English
RCDs	Rehabilitation Counselors for the Deaf
TRS	Telephone Relay Service
TTY	Text Telephone

About the Author

I first diagnosed my own hearing loss as a child. One day, I realized that the ticking of my noisy watch no longer bothered me when I held it out on one side. I cried a little, but didn't tell anyone, and promptly forgot about it for five years. By the time my hearing loss was officially diagnosed at age 15, while I was a freshman in college, it was already far advanced. At the time, it was a typical binaural (both ears) sensorineural loss, ranging from moderate at the lower frequencies to severe to profound at the higher ones. Typical, too, was the lack of rapport

that the specialists I saw had with their patients — one referred me for speech therapy (which many late-deafened people do need, but which I didn't) and another whipped out a temporal bone bank donation form. Nor was there any mention of assistive devices which could have been helpful to me. This has, I hope, changed over the years, but I'm still amazed at how little information newly diagnosed, late-deafened adults receive.

After giving a borrowed hearing aid a two-minute trial using a makeshift earmold, I forgot about my hearing loss for another five years. I entered a lengthy period of denial, and refused to consider wearing a hearing aid until I was well into graduate school. Even then, I wore the aid only sporadically, relying instead on my speech reading skills. When my backpack, with the aid inside, was stolen a few years later, I didn't replace it for several years. It would be years before I accepted my hearing loss and began to wear two aids during all my waking hours. Recently, I asked an old friend from Harvard, with whom I used to drive to New York on weekends, if she had noticed my hearing loss when we met during her first year as an undergraduate and mine as a graduate student. "Oh yes," she replied. "I couldn't talk to you at all in the car while you were driving because you always turned to face me so you could lipread. Since I used to sit in the back seat, you scared me half out of my wits."

I went through the same emotional trauma when it became obvious — to everyone but myself — that I could not handle voice telephone calls reliably. Although I still have amplified telephones of every make and model, I now use a TTY almost exclusively for my telephone conversations. (In Chapter 5, we'll discuss these keyboard-equipped devices with small screens on which you can type and read messages via the phone.) I went through yet another period of resistance before being able to call myself "deaf" comfortably.

My story is unusual only in the fact that I was able to function well academically and socially with a severe to

profound hearing loss for so long. For several years during grad school, I taught and even worked at the squash courts, where my main task was to take court reservations over an unamplified telephone. Somehow, I managed without any great trauma or frustration, but then I've always been able to make the most of the sounds I'm able to hear. Eventually, my loss reached the point where even I had to admit that I needed to learn more about available technology and coping strategies. I've been very fortunate to meet a number of people who have taken the time to help me and give me support.

Like many people with profound hearing losses, I've had to change my personal interests and career objectives several times: setting aside the violin, which I'd played since elementary school, changing majors in college, abandoning my goal of doing folklore fieldwork, and realizing that secondary school teaching was not the best career choice for me. I live alone and now run two businesses (my writing business and 11 rental cottages in Vermont) from my home office. After years of denial and researching solutions to my communications problems, I've made peace with my hearing loss.

Don't ever let anyone tell you that adapting to deafness is easy. It involves considerable upheaval, learning, and teaching. But it's a challenge that can be met, and the rewards in new interests, friendships, and increased self-awareness can be deeply satisfying.

1. The Impact of Deafness

■ Overview

Deafness affects every facet of life. Although most people who lose their hearing experience many of the same emotions and difficulties, each of us responds in a unique way. In this chapter, we'll look at the stories of some late-deafened people, discuss the emotional impact of deafness, and look at the way deafness can affect different areas of our lives.

■ Causes of Late-Deafness

Deafness later in life can have many causes. Among the more common ones are:

- tumors of the acoustic nerve (neurofibromatosis type II and acoustic neuromas)
- ototoxic medications
- meningitis
- accidents
- virus
- aging (presbycusis)
- exposure to loud noise
- Meniere's disease

See a doctor as quickly as possible if you experience:

- a sudden drop in hearing
- unexpected dizziness (vertigo)
- significant pain in the ear or head

In many cases, doctors cannot determine the cause.

■ The Meetingplace

In this section, we introduce a few late-deafened adults who are "making it in Massachusetts," as a former governor used to say. For some of you, it may be one of the first times you've met people who are late-deafened. The people we profile here aren't intended to be standards by which you should measure yourself. They're simply interesting folk who have faced deafness and built useful and rewarding lives.

Helen Fleming

If you were at the recent Deaf and Hard of Hearing Together Pledge Walk at the Hatch Shell in Boston, you probably noticed a crowd surrounding an animated white-haired woman decked out in a colorful warmup suit. Helen Fleming has been a key figure on the Massachusetts hard of hearing scene for many years. Her efforts on behalf of people with hearing loss have been recognized by the Boston Guild for the Hard of Hearing, Self Help for Hard of Hearing People, the Independent Living Center of the North Shore, and by Channel 6 (the Independent Spirit Award). She has served on the Board of Directors of the Boston Guild for the Hard of Hearing and the ILC of the North Shore, and on the State Advisory Council for MCDHH. Along the way, she founded the North of Boston SHHH Group and spent six years as state SHHH coordinator.

Helen's hearing loss was first diagnosed when she was a sophomore at Regis College, where she received a B.A. in English. "I had absolutely no idea the impact that this hearing loss was going to have on my life. I think that if I had been able to see down the road, to see some of the traumatic experiences that I have had, there is no way in God's world that I would have had the courage or the nerve to go on and do the things that I did."

Her first hearing aid came by way of a cookie boxtop that she mailed to a contest. She actually won a go-kart, but the company let her take the money instead, and she bought a hearing aid.

She went on to receive a master's degree in education from Salem State College. "I still thought there was nothing in the world wrong with me," she recalls. "I kept thinking: There is nothing in this world that I can't do if I make up my mind about it....I think that the first time I began to acknowledge that I was having trouble was when I was labeled — that's why I don't like labels. I think labels hurt people. When they said, 'she's hearing-im-

paired.' Impaired? Like there was something faulty. You know, the package isn't right, send it back."

She taught school for 40 years. During the final 20 years, she taught remedial reading. "And that was a real blessing for me. I only had one to five students at a time. That way, I was able to cover up." She was terrified that the parents of her students would find out about her hearing loss. She was even afraid to ask for a personal day because "they would think, oh, she's not capable of doing the job." Finally, though, she applied for a personal day so she could go to the annual luncheon of the Boston Guild for the Hard of Hearing to hear Rocky Stone, founder of Self Help for Hard of Hearing People. "He gave me so much to think about that day, I could not believe that a man who was deaf or that had to struggle in the hearing world could be so upbeat. And when I confronted him about that, he said, 'Aren't you upbeat?' I said...if I had the money, I'd buy a deserted island in the middle of the Pacific Ocean and I'd set up a tent and stay there. He asked why. I said so that I wouldn't have to listen to people.... I didn't mind talking to them. It's the listening that bothers me. He then said, 'No, no, no.' That was not a luxury any of us could have in this world. Like it or not, we had to listen."

When her husband died 15 years ago, it was like losing her hearing all over again because he had been so supportive. "I was an angry, angry person," Helen recalls. "And I didn't know what the heck I was angry about. I thought I was angry at my family because they wouldn't cooperate with what I needed. How could they know what I needed when I didn't know that myself? And that's how my involvement with Self Help for Hard of Hearing taught me how to cope. It taught me how to modify aggressiveness to assertiveness. It taught me how to manage stress. I'm still working on the stress part."

Helen has joined the world of telecommunications. She lives in Lynn with her computer and TTY, Bonnie and Clyde. Because deteriorating vision runs in her family,

Helen has successfully received a cochlear implant.

“So from the individual who thought there was nothing left for her to do, who was afraid to be in a crowd, afraid to get up in front of a microphone because she was going to make a mistake, this individual now feels that she still has plenty of miles left on her engine, but she has miles to go before she sleeps. And I hope I will be able to keep going as an advocate for the rights of hard of hearing people.”

John Anderson

It began the afternoon of Aug. 6, 1982 with a little light-headedness as John Anderson watched the movie, “E.T.” He went home and took an over-the-counter sinus tablet that night for his “sinus headache.” In the morning, when he put his hearing aid on his right ear, he noticed he could barely hear with it. After changing batteries and checking out the aid with his hearing aid dealer, John made an appointment with an ENT at Mass. Eye and Ear Infirmary (MEEI) and learned that his “better ear” had experienced a significant drop in residual hearing. A week later, he was deaf in both ears.

For the next four years, he participated in a variety of counseling sessions to adjust to his deafness, began what he called “a frustrating, but helpful, introduction to Deaf Culture,” acquired a hearing dog to become more independent, and was finally selected by MEEI to have a multiple channel cochlear implant. He was hooked up in June, 1985.

A year later, he and his wife divorced, and the following year, he changed jobs and became a project leader in application computer software development. In 1991, he became active in the Minuteman Implant Club and served as its president for four years. During that time, he married his present (hearing) wife, and in 1994, quit his job to begin a career change by working for the Massachusetts Commission for the Deaf and Hard of Hearing. Since

then, he has received a Master's degree in applied psychology from Antioch College. He will soon begin his new career at the Clarke School for the Deaf, working as an Adjustment Counselor in their mainstream center department.

Jane Sokol Shulman

"At first, the ENT thought the audiometer was broken," reports Jane Sokol Shulman. Her mild high-frequency loss had turned into a 30-40 decibel loss. It was the day of her 18th birthday.

She went off to Princeton. "I was tired all the time," she recalls. "I was frustrated. I didn't know quite what to make of these changes in myself. In my mind I ran through words like lazy, burned out, unmotivated, not living up to her potential. I was lonely." No one made the connection to hearing loss. Jane thought it was related to the death of her mother and the ensuing upheaval in her family, to ambivalence about her new independence. She got her first hearing aid as a senior in college. It was a traumatic experience. "The audiologist whose name, thank God, has been banished from my memory, fitted me with these two humongous behind-the-ear aids and he said with obvious satisfaction, 'Now you have normal hearing.' He wrote a prescription and sent me on my way.... The hearing aid prescription was for a brand and model sold by no one in New York City or within a 250-mile radius except for this audiologist's business partner. I felt abnormal. I felt defective. I felt ashamed," Jane recalls.

She went to graduate school, married, all the while losing chunks of hearing. Managing the biomedical research lab at Brigham and Women's Hospital led her into an MBA program. She received her degree with high honors without the benefit of any special help or assistive services, because, she says, "I had no idea at the time that they existed."

She began to call herself deaf, although it made her cringe. "It took me six months to be able to get the word

out, another six months to be able to say it without turning bright red and breaking into a sweat,” she says. “But something miraculous happened. I discovered that I truly **believed** that my ‘hearing problem’ was neither my fault nor within my capacity to prevent or control.... Replacing guilt, shame, and an overwhelming sense of inadequacy was a tranquil self-acceptance.”

Jane learned of the Association of Late-Deafened Adults (ALDA) when she bought her first TTY. She became president of the Boston chapter and brought an eloquence and insight to its newsletter. Under her leadership, the Boston group continued to expand in new directions. “For me, my overarching motivation was to do what I could so that my own experience of twenty years of isolation was not repeated.”

She became purchasing director at a biotech company, but lost her job to downsizing in 1993. She conducted a grueling search to find a job in her field, but was unsuccessful. “I am forced to conclude that despite my experience and despite my blue chip academic and work history background, despite the laws that were in force at the time and my explanations of assistive accommodations, my deafness was a major hindrance.” Private industry’s loss is the state’s gain. Jane is now bringing her considerable talents to her post as Administrative Services Coordinator at the Massachusetts Commission for the Deaf and Hard of Hearing.

Annette Posell

Blue, who happens to be a brown and black German shepherd, is lying under the table, happily extracting the marrow from a bone. A few feet away, Blue’s owner is alternately speaking to one member of the State Advisory Council to the Massachusetts Commission for the Deaf and Hard of Hearing, speechreading the replies, and signing to two other people.

Annette Posell is that rare combination: a late-deafened person who is totally at ease in both the hearing world and the Deaf community. Here is her story.

One night when she was 16 and a junior in high school, she was awakened by a “blasting headache” accompanied by ringing in one ear, vertigo, and nausea. “I literally crawled into bed,” she recalls. For the next six months, the symptoms came and went, leaving less hearing each time. She spent long periods of time in the hospital but the neurologists were baffled. Within six months, she was totally deaf, but she felt grateful to be alive.

She knew nothing about deafness. There were no TTYs, no flashing signals. She hated not being able to use the phone like other teenagers, and was terrified to return to her large public high school; her father insisted that she needed the social life of school. It was during the Elvis years and she missed the music, but her friends kept her abreast of song lyrics and new singers, took notes for her in class, and studied with her.

Her parents and guidance counselor ruled out Gallaudet University in Washington, D.C. (the only university in the country for deaf students, most of whom use ASL) fearing that she would “lose speech,” and the other colleges where she applied rejected her because of her deafness. She found a home at the College of Wooster, “a small liberal arts college with a big heart,” and graduated with her class, having formed many lasting friendships and motivated her freshman roommate to pursue a career in speech pathology. The only job she could find was in the deaf unit of a state school for mentally retarded women. Here, she quickly picked up the basics of sign language and decided to become a teacher of deaf children. Accepted at both Gallaudet and Teachers College at Columbia University, she chose the latter to be near her husband, who was getting a doctorate from Rutgers. “Again, same as Wooster,” she recalls. “No interpreters and no legislation guaranteeing any rights. I lipread my way through school and relied on notes from friendly class-

mates. One coping strategy I found was to read everything in the teacher's bibliography...and get notes from two or three classmates and combine them.... Lots of work...." After receiving her Master's in Special Education, she taught in a variety of settings for 12 years.

She joined The Caption Center at WGBH to help with an educational project, and was sent out on the road as the deaf spokesperson, which led to her present job of Manager of Corporate Development. "It is a rewarding job, never, ever boring, and The Caption Center and WGBH have been wonderful to me. I work in a hearing environment, providing a service originally intended for deaf and hard-of-hearing people. I always have interpreters available...and the people I work with have unconditionally and generously provided whatever assistive devices I need to accomplish my work successfully."

Annette has been active in the education of her two hearing children. "Much of my current life is spent in the hearing world and my primary communication mode is still speaking, but I feel comfortable in the deaf community and appreciate having friends who can hear and those who don't....I am grateful that I can sign, speak, and lipread and bounce between both worlds."

■ Why Do I Feel the Way I Do? The Psychological Impact of Deafness

Each of us reacts differently to deafness. Our reactions depend on many factors, among them:

- the nature of the hearing loss: was it sudden or progressive?
- our individual personalities in general, and the way we respond to adversity and challenges, in particular
- our maturity, independence, and flexibility
- the support we receive from friends, family, employers, co-workers, healthcare professionals, and other

people who are deaf

- what else is happening in our lives at the time
- what is important to us

Nevertheless, there seem to be patterns in the way people behave, and it's useful to know what they are so we can better understand some of the emotions we may be experiencing.

Hearing Loss as Trauma

Acquired deafness is a traumatic loss, particularly for people who lose their hearing suddenly. It turns the way we relate to other people and to the world completely upside down. This is unique to late deafness; people who are born deaf never feel this overwhelming sense of loss because they've never experienced what we've lost.

Let's look more closely at this. At a recent workshop, Dr. Michael Harvey spoke about the basic needs of all human beings and how deafness affects most of these needs. Dr. Harvey is a psychologist who has done a great deal of work with late-deafened, hard of hearing and Deaf people. More information is available in **Psychological Effects of Acquired Deafness: A Training Guide** by Harvey and Howe (1996).

- We need to feel that the universe is "just, meaningful, and controllable," to quote Dr. Harvey. To give a trivial example: we can predict that when we drop a coin, it falls. The day that coin rises, or hangs in the air, or behaves randomly, we've lost some of the stability of our lives. Somehow, the rules have changed. That's exactly what happens when we become deaf. Through no fault of our own, our lives and bodies have become unpredictable. What's more, we can do little about it.

Remember what Helen Fleming said? "I still thought...there is nothing in this world that I can't

do if I make up my mind about it.” A number of years ago, Avis mounted an ad campaign around the slogan “We try harder.” It may work for rental car companies, but trying harder won’t make us hear. “One of the hardest things to accept,” says Jane Sokol Shulman, “is that working harder will NOT solve the problem.”

- We need to feel independent, able to function competently in the world and have some measure of control over our own lives. Closely related to this is our need to feel safe. Deafness also attacks this. We can no longer hear the footsteps behind us, the engine noises that warn us of an approaching car, or any of a thousand little things we’ve come to expect.
- We need to feel connected to the world. Dr. Donald Ramsdell in **Hearing and Deafness** (by Davis and Silverman, 1978) has noted, “sound serves...as the *auditory background* of all daily living.” We have grown accustomed to a background of noise in our lives—birds chirping, wind blowing, sounds of traffic, for example—so accustomed that we are barely aware of it and may even find it bothersome when we stop to listen. “These incidental noises maintain our feeling of being part of the living world and contribute to our own sense of being alive.”
- We need to feel that we belong to some larger group. Deafness distances us from the hearing world to which we have always belonged.
- We also need to feel that our lives have value, the “self esteem” that everyone talks about these days. Most of us have a long road before us to regain this sense. There is a constant feeling that maybe we’re not trying hard enough or maybe we aren’t smart enough to understand people, or that our deafness is in some way a flaw in our own characters. After we’ve listened to people say, “It wasn’t important, anyway” a thousand times, we begin to feel that

maybe we ourselves aren't important. And this is a terrible blow.

We could go on and on about this, but the point is clear that for adults who become deaf, the sense of loss can be devastating. It is fully understandable that they go through a grieving process that may last many months, even years. The effect is probably greatest for those people who suffer a sudden hearing loss, but it also accompanies severe and profound progressive hearing loss. A day arrives when they realize that they can't hear the doorbell ring, the sound of running water, or a flushing toilet, or any of a hundred things. At that moment, the sense of loss is overwhelming.

"I've always known I would probably be deaf one day. The signs were all too clear: the life-long progressive loss, and the right ear, dead now for two years, was surely a clue. I was in no way, however, prepared for the shock and trauma of the reality of near-total deafness," writes Paula Bartone-Bonillas in an article in **Hearing Health**.

Let's look at some of the reactions people often have to their late deafness. These stages don't occur in neat sequence; climbing out of one doesn't necessarily mean that we leave it behind forever. Depending on what is happening in our lives, we sometimes go back and forth from one stage to another. We shouldn't think of these stages as "bad," something to be avoided. Deafness is traumatic, and we need time to adjust to it. Grief is a very natural reaction and, for most people, crucial to the healing process. Before we can come to terms with our deafness and get on with our lives, we must grieve for what we have lost. In many ways, life will never be quite the same, but *different* doesn't necessarily mean *worse*.

"When in a crowd, as at the mall, I feel like I am inside a plastic bubble which separates me from the rest of the world. This feeling of isolation prevents me from appreciating my surroundings."

— Blake Putney

Isolation and Loneliness

Newly-deafened people almost universally report a feeling of isolation and loneliness. Blake Putney, on the email discussion group “Beyond Hearing”, described it as living in a “bubble;” others sometimes talk of a “glass wall” that separates them from the rest of society. The isolation exists on two levels. On the sensory level, we may miss the sounds of life that formed a background for living, or we may find ourselves surrounded by a babble of unintelligible voices. On the social level, we are caught betwixt and between worlds: “Audiologically deaf, but culturally hearing” is the way one author put it. We no longer feel like full-fledged members of the hearing world, but we don’t belong to Deaf culture, either. There’s a feeling of exclusion.

How do we deal with this feeling of detachment? The best way is probably to meet or correspond with other people who have become deafened. By learning that we are not alone, we validate our own emotions and become able to make new friendships, learn how others have dealt with their deafness, and find a place for ourselves in society. We’ll introduce you to several important support groups in the next chapter.

Denial and Projection

There is a stigma attached to hearing loss in our youth-oriented country, a belief that only the elderly lose their hearing. It’s nonsense, but we may feel that to admit being deaf means that we are getting old. Particularly for people who experience a gradual loss of hearing, denial is a common response. As you’ve seen from my own story, I simply refused to acknowledge my hearing loss until it was severe to profound. In my case, this wasn’t terribly damaging. I still went to concerts, talked on the phone, performed well in school, had a wide circle of friends. But it certainly would have made my later adjustment easier if I’d faced the truth earlier. For many people with progressive losses, denial is a very real problem and uses a great

deal of energy that could be better directed toward improving communication skills. Unfortunately, many people wait years before even getting fitted for hearing aids.

Another way that denial frequently manifests itself is in our difficulty with saying the simple words “I’m deaf.” In the late-deafened community, it’s sometimes laughingly called “the d-word.” It seems like a very minor point, but for most of us, those words somehow seem to symbolize the entire situation, which we may be fighting against with all our energies. For many people, moving from “hard of hearing” to “deaf” is a major step.

Nevertheless, denial can have a very real emotional benefit. It allows us to lessen the impact of deafness, to handle it in small doses instead of as a single blow. But when denial continues too long, it becomes harmful. It slows down our progress towards the next stage and delays our meeting other late-deafened people and learning new communication strategies. And in many instances, it leads us to bluff our way through conversations, which at best, means that we get nothing from them or try to control discussions by talking all the time, and, at its worst, leads to embarrassing situations or costly errors that further lower our self-esteem.

For Family and Friends

How do you help someone who is in denial? It’s very difficult. In the first place, make sure that you yourself have come to terms with the loss.

Don’t make excuses for the deafened person: “The acoustics in that hall were awful!” “That actor mumbled his lines.” Don’t coddle or overprotect the deafened person out of a false sense of compassion. Be honest. For example, staying home with your late-deafened spouse rather than joining friends for dinner, under the pretense that you aren’t interested, will only foster a sense of sacrifice and resentment on your part.

For some people, a kind of shock treatment can be very helpful. In graduate school, I met and became friends with someone who was hard of hearing. She saw immediately what I was doing. When she called on the telephone and sensed that I wasn’t following the conversation, she would bark, “What did I just say?” I was ready to kill her, but it made me realize how little I was actually hearing of our conversations.

Continued

For Family and Friends (Cont.)

But perhaps the best way to help is to be patient, knowledgeable, and understanding. Taking the initiative to learn about support groups and other resources (Chapter 2), assistive technology (Chapter 5), auxiliary services (Chapter 6), and communication skills (Chapter 4) can be very helpful. Offer to help with speechreading or enroll together in a sign language class. Offer the information, but only if the person seems receptive. Try to be calm and patient, admittedly difficult when dealing with such an emotional issue with a late-deafened person who may be very angry and confused.

What psychologists call *projection* is a frequent accompaniment to denial. Late deafened persons may say the reason they can't follow the conversation isn't because they can't hear. They say it's because people don't enunciate clearly these days, or because they really didn't want to listen to that silly lady's nonsense, for example. There may, of course, be some truth to these assertions, but the real reason they didn't hear is because they're deaf.

Anger

It's only natural to feel angry when terrible losses befall us

through no fault of our own. The anger is sometimes directed at the universe, or toward God, the medical profession, or one's family. It's easy to become caught in a bad case of the "Why me's?" The sooner we realize that often no one is to blame for uncontrollable things that happen, the sooner we can re-direct our energies in more positive ways. "It is okay to be angry at times," writes mental health therapist Maureen Mann, who herself has a severe hearing loss, "but it is not okay to hold on to that anger until it destroys your self-image, controls your life, affects your relationships with your loved ones, and damages or inhibits your career."

Depression

We would be less than human if we didn't become depressed when we first become deaf. We have, after all, suffered a great, incomprehensible loss and may feel like helpless victims. Depression can be overwhelming, almost paralyzing. During this stage, we need compassion and

support from friends, family, and the medical profession. We need, above all, to try to talk about how we feel. As we put our feelings into words, they become more manageable. "The very act of telling the story to another human being who cares, who listens, who attempts to understand, is part of healing," says Harvey. We begin to see that with creativity and hard work, and "a little help from our friends," we may be able to make changes that will help us in difficult situations. However, if your depression is prolonged or interferes with your life, you should find a professional with experience in treating people who are deaf. Contact the Massachusetts Commission for the Deaf and Hard of Hearing. Speak with your doctor. Depression is treatable.

Acceptance

The goal of adjusting to deafness is to acknowledge it so we can get on with living our lives. This involves renouncing the role of victim, moving past the things we can't control and taking control of things we **can** control or change in our lives, moving from withdrawal to active participation. It's the point when we realize that we remain basically the same person as before, that we ourselves are in no way damaged, only our ears are. This allows us to adapt old relationships, form new ones, and personally grow from the experience of having to surmount great personal loss and suffering.

Acceptance doesn't mean that we will never again miss sound. A miscommunication with an insensitive co-worker, the birth of a child we will never hear, a concert by a favorite musician, and similar events can all trigger emotions that we thought we'd laid to rest. The pain may never completely fade, but in time, we become desensitized to such situations and they become easier to handle or even laugh at. Helen Sloss Luey and Myra S. Per-Lee, in **What Should I Do Now? Problems and Adaptations of the Deafened Adult** (Gallaudet 1983), have even suggested that "it is not realistic to expect total

acceptance, and it is likely that discussion of acceptance in the literature and by professionals has contributed greatly to people's feeling of inadequacy."

■ The Effect of Deafness on "Real Life": At Home, Work, and Play

It's difficult for hearing people to understand just how fully deafness pervades our lives. We'll discuss this in detail in Chapter 8, where we discuss coping strategies. This section describes some of the ways deafness can affect everyday relationships.

Family and Friends

After you become deaf, you and your family and friends will have to re-write the "rules" about the way you interact. Much of this will be through trial and error.

Family and friends often go through a process of grief, too. I have stacks of clippings describing all kinds of new research into "cures" for hearing loss, from acupuncture to vitamins to cochlear implants. They were sent to me by well-meaning people who were searching for a magical cure for my ears. Your deafness may be very hard for family and friends to accept. In addition to their distress at watching helplessly as you suffer through the first stages of shock and grief, it also makes them think about other painful topics: growing older, death, changes in family roles, etc. And it may make subtle changes in the way the family "works." The kids may no longer be able to yell for Mom when they need a glass of water in the middle of the night. Dad may no longer be able to mediate family arguments. Your book discussion leader may no longer be able to follow group discussions. Jobs may change; careers may take detours. "Your experience has been so intense that you cannot possibly emerge from it unchanged," write Luey and Per-Lee. "...Perhaps you have found more internal strength than you knew existed. Your priorities may have changed, and you may view the world and other people with new sensitivity, seriousness, and

compassion. Some people may not understand or accept the new person you have become." Late-deafened adults almost universally speak of finding out who their "real friends" are when they become deaf. Losing old friends isn't fun, but you can compensate by making new ones, strengthening old friendships, and exploring new areas of interest.

Jettisoning insensitive family members isn't so easy, of course, although all of us, hearing and deaf, no doubt have at times been tempted. Making family and marriage "work" is a job for everyone involved. You will have to be open and honest with each other. You must take the initiative and explain how others can best communicate with you; the suggestions, which we'll discuss in Chapter 4, are fairly simple, but changing ingrained communication patterns is always difficult. The best policy is probably for everyone to be upfront about their concerns and frustrations. You may need to explain that speechreading is very tiring, that you sometimes have to go off by yourself to recharge your batteries. Or you may have to set down rules for telephone conversations with other family members. There is nothing quite as maddening as watching a spouse have a 15-minute conversation with a son away at school, only to have the conversation summarized for you in a single sentence.

In many families, certain members fall into the role of "interpreters." They answer telephone calls, help with conversations at social functions. This can lead individuals to become dependent, or, alternately, to be resentful that their independence is being usurped. And the "interpreter" can feel burdened and angry. It's best to discuss these matters together and find out what is best for everyone. A successful solution will be one which meets

"At the dinner table, family members take turns, in a very natural way keeping me posted: 'Rocky, we were talking about...' 'Dad, we are discussing...' And so it goes throughout the meal.... The effort being made on my behalf goes far beyond the courtesy of keeping me involved. It is an act of love."

— Rocky Stone in *An Invisible Condition: The Human Side of Hearing Loss*

your special needs but is also considerate of other members of the family. Each of you will have to try to walk a mile in the other's shoes.

Although it's always useful to find out how other deafened people handle the problems we face, what works for them may not be quite right for you. Many late-deafened people, for example, become furious if a family member doesn't let them conduct their own telephone conversations, but rather "helps" them out. For me, that isn't a problem. At my summer business in Vermont, when the phone rings, I often ask whoever is around to take the call and "translate" for me. I don't feel that I'm surrendering my independence. I don't need practice making business calls or explaining how callers can tell me their phone numbers so I can call back using the Telephone Relay Service (see Chapter 6). For me, it's a question of efficiency. My own telephone calls using a TTY are very tedious and time-consuming. If a working pair of ears happens to be in the house, I just make use of it. But other late-deafened people feel very differently.

"The resolution of communication problems and the resulting rifts in relationships, does not require major alterations in the ways in which families do things," writes Dr. Sam Trychin, whose workshops on coping strategies for hard of hearing people have become almost legendary. "Rather, it is more frequently a matter of changing a little something here and a little more there. A number of minor adjustments in behavior can easily add up to major changes in attitudes, expectations, and emotions."

At Work

You will need all your creativity, energy, and people skills to optimize your work situation. We'll discuss ways of dealing with specific problems in the remaining chapters. You may find that you can, to some extent, control your listening environment. You can train co-workers in communication strategies (see Chapter 4). You can make use of assistive technology (see Chapter 5) and auxiliary

services (Chapter 6). You may have to change your role and responsibilities, or even change your career goals. This is another area where the support groups we'll discuss in the next chapter can be invaluable.

In her book, **Coping with Hearing Loss** (Barricade Books), Dr. Susan Rezen, Professor of Audiology at Worcester (Mass.) State College, suggests that you hold a training session for your co-workers to explain your hearing loss, suggest communication strategies, and discuss how to maximize your benefits from speechreading and hearing aids, if you wear them. Some companies can be very responsive. We saw how The Caption Center has provided Annette Posell with interpreters and assistive devices. In Chapter 8, we'll discuss what accommodations companies are required by law to provide for you. When product engineer Howard Samuels lost his hearing several years ago, the **Boston Globe** reported how the company for which he worked, Analog Devices in Wilmington, offered his co-workers American Sign Language (ASL) classes on company time, captioned the videotaped annual reports, and provided him with a number of assistive devices. Samuels, who had been with the company for 11 years and was fluent in Japanese and French, was grateful to the company and his co-workers, but quick to point out that Analog Devices' efforts were a good business investment, because they enabled the company to retain an experienced employee in a useful and productive role; "It costs a lot of money to bring one skilled employee like myself to the company," he explained.

Nevertheless, sometimes it just isn't possible to continue in your present job or even at your present company in another capacity. Losing one's job is a wrenching experience. For starters, you may want to sit down and analyze your strengths and weaknesses. You can consult case managers at the Massachusetts Commission for the Deaf and Hard of Hearing, speak with Independent Living Specialists for the Deaf and Hard of Hearing or Rehabilitation Counselors for the Deaf. Chapter 2 discusses some of the support services that are available to you.

Many late-deafened adults, after learning sign language, have discovered that this new skill presents new job opportunities and opens alternative career doors. Many, having experienced the trauma of deafness or even come near death, find that their focus and goals have changed; different things have become important. A common thread runs through discussions with many late-deafened and severely hard of hearing people: "My own experience was so difficult, I want to do something to insure that other people don't have to go through the same suffering," they say. "I began to realize," said Jane Sokol Shulman, who now works at the Massachusetts Commission for the Deaf and Hard of Hearing, "how different and how less painful my own experience might have been had I received information and support earlier in my journey." John Anderson left the software industry to become a counselor and now works with deaf children in mainstream programs. Helen Fleming has spent her retirement advocating for hard of hearing people. Annette Posell works at The Caption Center, which provides a valuable service for people with hearing loss. I'm writing this book.

Recreation and Social Life

Does deafness spell the end of social life? Certainly not, as long as you bring a certain flexibility and creativity to the situation. After all, one of the favorite activities at gatherings of the Association of Late-Deafened Adults (ALDA) is karaoke! In Chapter 5, we discuss assistive devices you may be able to use; Chapter 8 describes coping strategies that can be of some help. You can probably do everything you did before you lost your hearing. You may just have to do things differently or not as well, but that doesn't mean you can't enjoy yourself. As we'll see, there are captioned movies, quiet corners of restaurants, and smaller, more intimate dinners. Town meetings and church activities become accessible with assistive listening devices and interpreters. Many deaf people are excellent dancers, able to feel vibration through the floor or pick up the low frequency beat. A knowledge of American Sign

Language opens doors to activities within the Deaf community and new friendships. Support groups like ALDA and Self Help for Hard of Hearing People host frequent gatherings and like any other meetings, usually begin with some socializing. The annual conferences of these groups are opportunities to meet old friends, make new ones, and see new sights.

■ Special Concerns of Senior Citizens

The incidence of hearing loss increases dramatically with age. Many of the difficulties of late deafness are magnified for the elderly population:

- Some seniors may not be as comfortable with new technology as younger people. They may shy away from using assistive listening devices and closed captioning feature on new television sets because it may seem to be complex. They may lack the manual dexterity to manipulate the controls on hearing aids and assistive listening devices, and may be unaware of adaptations that eliminate such difficulties.
- It's hard enough to adjust to deafness in the familiar, comfortable surroundings of one's home. Many seniors who have moved into nursing homes or live with relatives find themselves in an unfamiliar and somewhat hostile environment that makes adjustment even more difficult. The Massachusetts Commission for the Deaf and Hard of Hearing often holds training sessions for staff of nursing homes to sensitize them to the problems, characteristics, and needs of individuals who are severely hard of hearing or deaf, and to teach ways to improve communication.
- Seniors may feel very anxious about maintaining their independence and their ability to live in their own homes, yet may be unaware of or avoid using safety alerting devices and other assistive technology (Chapter 5). As a result, deafness and its associated

“incidents” (bathtubs that overflow, kettles that boil dry, doorbells unanswered, etc.) may threaten their independence, leading to further anxiety and depression.

- It’s dangerous to generalize, but as a group, seniors tend not to be as assertive as younger people and seem to shy away from calling attention to themselves. Hearing aids and assistive devices might make them seem “different.” Connecting with peers at SHHH and ALDA groups can be very helpful.
- They may experience great disappointment in not being able to hear their grandchildren’s voices and participate fully in family gatherings. Inappropriate answers, due to not fully understanding the conversation, may be taken as evidence that “Grandma’s mind is beginning to wander.”
- Deteriorating vision, another common accompaniment of aging, can make speechreading difficult. If reading is already a chore, then the individual may spend more time watching television or listening to the radio. Deafness may make this unavailable without assistive technology, further disrupting life.

Nan Robbins, former Deputy Commissioner of the Massachusetts Commission for the Deaf and Hard of Hearing, recalls her paternal grandfather, who was deafened as the result of an accident while working on the railroad.

“Looking back, as a young child I was rather mystified by him, not really understanding that he could not hear well at all or just what that meant in practical terms. ... I was not exactly afraid of him, just remote from him....My child-speech was probably very difficult for him to understand, I now realize. And looking back, the family was not very clever in “getting it” about his hearing loss, and how to communicate more easily. The strategy, I suspect, tended to be avoidance rather than accommodation. Today, hearing aids are vastly improved, and there is much more information available to families to assist communication with the deaf family member.”

For more information:

Contact MCDHH for information sheets of interest, including a bibliography.

■ Special Concerns of Teenagers and Young Adults

Like seniors, teenagers don't want to be different from "the crowd." Unlike seniors, they also feel a sense of their own invulnerability.

When Helen Fleming learned that she had a progressive hearing loss, her reaction was in many ways typical. "Being 19 years old my attitude was, so what? What the heck's wrong with not being able to hear okay? I'm very lucky. I have two feet, I have two arms, I have a good head. I have excellent vision. What am I worried about? So I can't hear a little bit."

For teens who become totally deaf, the situation is different, but many of the concerns are the same. Annette Posell, whom we also met at the beginning of the chapter, became deaf over a period of six months at the age of 16. She says that losing her hearing changed her life, but it wasn't a particularly sad experience. "I had youth on my side," she says. "And I was very sick and thought that I would die, so becoming deaf was not so much compared to that." In school, the fact that she couldn't hear was "the only difference between me and the other students."

She remembers how relieved she was when the audiologist told her that hearing aids would be useless. "I did not want to use a hearing aid because at age 16, boys were just beginning to interest me. The thought of a boy putting his hands through my hair and getting wound up in wires was too much!" (Hearing aids at that time were large and cumbersome.) What she hated most was not being able to use the telephone herself. (TTYs were not yet available.) Her parents "would have the conversation, and tell me about it after they hung up." Her brother seemed overprotective and her father made her take a special driving test he concocted. She was terrified of

returning to her large public high school, but her friends helped her out in many ways. However, nobody at the school seemed to know how to deal with her. An English teacher tried to remove her from his class. “I credit him now, although I hated him then, for creating in me a drive to prove I could do something that people said I could not. I got an A in his class only because I felt the need to prove him wrong!”

What help is available today

Annette became deaf quite a few years ago, before many services and technological advances were in place. Today, the law, support groups of others who become deaf, assistive technology, and auxiliary services are readily available. You’ll find information on these topics throughout this book.

- **Emotional support:** Talking with peers who have become deaf or adults who became deaf when they were teenagers can be very helpful, as can talking with a special counselor or therapist about adjustments and feelings. There are a number of therapists and counselors in Massachusetts who have special training and understanding about deafness. Some of them are themselves deaf or hard of hearing.
- **Access to the telephone:** Annette found her inability to use the voice telephone a major problem. Today, teenagers who become deaf have a lot of resources in this area (Chapter 5). Today we have TTYs, the Telephone Relay Service, fax, and email.
- **Access to what the teachers are saying:** Most teenagers who become deaf take classes to become proficient in speechreading (Chapter 3). Especially if some residual hearing remains, speechreading can be very useful, more so when used with other communication strategies (Chapter 4).

Some late-deafened students use Oral Transliterators

(Chapter 6), so that a very clear “picture” of what the teacher and other students are saying is available. In addition, many teenagers decide to learn American Sign Language (Chapter 3) so that they can use ASL Interpreters in classes, and also so they can meet Deaf individuals who can give tips on life as a Deaf person. Today, several high schools offer classes in ASL, some for foreign language credit. Schools are usually quite willing to educate students and staff about hearing loss, communication between deaf and hearing people, and American Sign Language.

During the past several years, Communication Access Realtime Translation (CART Service; see Chapter 6), in which the spoken proceedings are projected on a screen, has become available and is used by many late-deafened students in high schools and colleges to provide access to lectures and group discussions.

- **Practical information about relationships and social activity:** Information about socializing with hearing partners, how to deal with parties, etc. is best gleaned through talking with others who know. Make connections through the Association for Late Deafened Adults, the MCDHH, SHHH, and sometimes the DHILS Programs and services (Chapter 2).
- **How laws help:** State and federal laws require schools to provide certain special services (listening systems, interpreters, CART service, counseling, tutoring, and so on). In elementary through secondary schools, such services can be obtained by stipulating them in the Individual Education Plan (IEP) that students with special needs (including hearing

loss) can file. Special services at the college level are also required in most circumstances. Information is available from the Massachusetts Rehabilitation Commission, Rehabilitation Counselors for the Deaf; and also from MCDHH and the DHILS services (Chapter 2), and to varying degree, from your local school department.

For more information:

Use the Massachusetts Commission for the Deaf and Hard of Hearing as a central point of contact and information.

2. Where to Turn for Help

When the sounds you have heard all your life suddenly stop, it's natural to feel isolated and excluded. But you are not alone. Late deafness is fairly common and there are many shoulders to lean on. In this chapter, we discuss support groups and services that can help you adjust.

■ Support Groups

Most late deafened people coping with a hearing loss find it helpful and reassuring to meet others who are in the same boat and have experienced the same emotions and difficulties. There are several national organizations, with chapters in the state, each with a different focus. If you speak to members of these groups, many will tell you the same thing: that the support group has become a second family, a refuge where they are fully accepted and their communication needs are understood.

Association of Late-Deafened Adults (ALDA)

"Since its founding over nine years ago, " writes ALDA-Boston past president, Carol Menton, "ALDA has been a state of mind as well as a thriving international group for folks with acquired deafness. Its communication philosophy of 'whatever works' is what ALDA is all about. The organization promotes peer connection, support, and mutual respect for the various choices that members make about communication and life with hearing loss. Through its newsletters, annual convention, national and local advocacy, and local chapters, ALDA provides a network of connections and support for those who've become deaf after having acquired spoken language. New members are warmly welcomed!" Both the national and Boston organizations publish quarterly newsletters, **ALDA News** and **ALDA-Bostonian**, respectively. ALDA will host a convention known as ALDA Con in Santa Fe, New Mexico in November, 2000 and Newport, Rhode Island in October 2001.

Kathryn Woodcock, the first deaf president of the Canadian Hearing Society and a former ALDA board member, has written about ALDA's official communication policy: "whatever works." "If that entails standing on your head and blinking in Morse code, then we try to work with that. Pencil and paper, keyboards, cochlear implants, fluent sign language, lousy fingerspelling, lipreading, and a great deal of laughing are all observable at ALDA gatherings."

"In the course of buying my first TTY in the summer of 1991, I saw a newsletter from ALDA-Boston...and made contact with them...To me, it meant my first encounter with another person who had experienced adult-onset hearing loss...Twenty years after my first medically documented significant hearing loss, finally for the first time I met another human being who had gone through what I went through."

- Jane Sokol Shulman

For more information:

- ALDA-Boston chapter (serves members across the state)
P.O. Box 323
East Bridgewater, MA 02333-0323
info@aldaboston.org
- ALDA (this is the national office)
1131 Lake Street, #204
Oak Park IL 60301
877/907-1738 (voice/fax)
708/358-0135 (TTY)
www.alda.org

Self Help for Hard of Hearing People (SHHH)

"Self Help for Hard of Hearing People, Inc. is a volunteer, international organization of hard of hearing people, their relatives and friends. It is a nonprofit, non-sectarian educational organization devoted to the welfare and interests of those who cannot hear well."

Founded in 1979 by Howard "Rocky" Stone, SHHH has grown to be the largest of the national support groups for people with hearing loss, with over 250 local chapters across the country. Members span the continuum of hearing loss. The national organization publishes a bi-monthly journal, **Hearing Loss**, and holds annual conventions each summer. New Orleans in 1999, St. Paul in 2000, and Cherry Hill, New Jersey in 2001. SHHH has published a large number of reprints, booklets, and information packets, and sells books about hearing loss from its national office. The organization has taken a leading role in advocating for people with hearing loss. There are local chapters of SHHH throughout the state. They publish their own newsletters, hold monthly meetings, and provide peer support.

For more information:

- Self Help for Hard of Hearing People, Greater Boston Chapter, Inc.
P.O. Box 95, Essex, MA 01727
617/720-2196 617/787-8167 fax
<http://www.shhh.org/html/ma.html>
<http://www.shhh-boston.org/>

The Boston group has a listing of chapters across the state.

- Self Help for Hard of Hearing People, Inc.
7910 Woodmont Ave., Suite 1200
Bethesda, MD 20814
301/657-2248 (voice) 301/657-2249 (TTY)
301/913-9413 (Fax)
Web page: <http://www.shhh.org>

Cochlear Implant Club International (CICI)

"CICI is a non-profit organization dedicated to educating and supporting cochlear implant recipients and their families; advocating and promoting cochlear implants." The organization publishes a quarterly magazine, **Contact**, and holds a bi-annual convention.

For more information:

- Cochlear Implant Association, Inc.
5335 Wisconsin Ave. NW, Suite 440
Washington DL 20015-2034
202/895-2781 (Voice)
202/895-2782 (Fax)
info@cici.org
www.cici.org
- Minuteman Implant Club
209 Rolling Ridge Road
Amherst, MA 01002
413/549-4108

Acoustic Neuroma Association (ANA)

The ANA is a "patient-organized information and mutual-aid group....The ANA provides information and support to patients who have experienced an acoustic neuroma or other benign problems affecting the cranial nerves."

For more information:

- Acoustic Neuroma Association (ANA)
600 Peachtree Parkway, Suite 108
Cumming, GA 30041
770/205-8211 (voice)
770/205-0239 (fax)
e-mail ANAusa@aol.com

The NF2 Crew

A fairly new group, the NF2 Crew is “an informational and support group for people with NF2 [ed. note: Neurofibromatosis Type II, recurring tumors affecting the auditory nerve] and their family members,” conducted through email messaging.

For more information:

- www.nf2crew.org
- webmaster@nf2crew.org

■ Organizations Offering Support Services

There are also several agencies and organizations that fer peer counseling, support, and other specialized services for late-deafened adults.

Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)

MCDHH is a state agency and the central agency for information and a variety of specialized services for Deaf, late-deafened, and hard of hearing people in Massachusetts, for their families, and for providers of services.

MCDHH is often a good place to start when you are looking for information or assistance. For example, MCDHH provides:

- general information and referral
- direct information and education for consumers about topics related to communication
- case management services (see below) for children and adults
- information on assistive technology
- Interpreter and CART Referral Services

Continued

- payment for CART and Interpreter Services in many situations where other agencies are not mandated to pay
- training in how to provide communication access for private, public, and state agencies
- referral to self-help groups where you can meet other people who are late-deafened or have a hearing loss or are Deaf

“Both the Boston Guild and particularly Self Help for Hard of Hearing People were responsible for my rebirth. They gave me so much confidence. I’ve accomplished things in my life in the past 15 years that I never thought I would ever be able to do.”

— Helen Fleming

- assistance in finding appropriate services and programs

The **Department of Case Management Services** at MCDHH employs bilingual staff who are fluent in English and American Sign Language. Many are Deaf, hard of hearing, or late-deafened themselves. Here are a few of the questions that the Case Management Services Department can help you answer:

- What can I do to cope at work, at home, and in the community?
- What assistive technology can I get to help me feel safe at home?
- How can I learn to speechread better?
- How can I know how to identify a qualified hearing aid dispenser?
- I am curious about American Sign Language and signed English. Where can I visit a class or meet people, including late-deafened people, who are

studying either of these?

- Where can I go to get financial aid?
- Is there technology available to help me in the workplace?
- My life is just falling apart. Who can help me?
- What special services and programs are available to help me?

When you call or visit, you will probably first speak to the case management referral specialist, who can answer your immediate questions and advise you of other sources of help or refer you to other specialized staff of the Commission.

For more information: Individuals may contact the Case Management Services Department at

- Massachusetts Commission for the Deaf and Hard of Hearing, attn: Case Management Services
150 Mt. Vernon Street, Suite 550,
Dorchester, MA 02125
617/740-1600 (voice)
617/740-1700 (TTY)
617/740-1699 (fax)
Email: MCDHH.Office@state.ma.us
(offices also in Springfield, Worcester and Plymouth)
web site: www.mass.gov/mcdhh

DHILS (Deaf and Hard of Hearing Independent Living Services/Programs)

There are ten DHILS programs in the state. They serve Deaf, late-deafened, and hard of hearing people, providing independent living services such as peer support and peer counseling, emergency intervention, self-advocacy training, assistive technology demonstrations and loans, sign language classes, and training in a variety of communication and life skills. The DHILS programs are staffed

primarily by individuals who are Deaf, late-deafened, and/or severely hard of hearing. Services specifically for late-deafened people vary somewhat from program to program.

For more information:

- Contact MCDHH for the current DHILS list or visit the MCDHH

Boston Guild for the Hard of Hearing Peer Counseling

The Boston Guild for the Hard of Hearing has been providing services to people with hearing loss since 1916. Each month, the Guild hosts a peer counseling group. All late-deafened and hard of hearing people are welcome to come in and discuss problems, solutions, and issues that arise in their lives due to hearing loss. The meetings are currently organized by Helen Fleming and Ellie and Matt Espinola. After the discussion, the group watches a closed-captioned movie. The Guild also offers many other programs for hard of hearing people, including speechreading classes.

For more information:

- Boston Guild for the Hard of Hearing
Northeastern University, Audiology Services
617/373-2492

Computer Forums and Support Groups

Both America Online (AOL) and Compuserve have forums for discussion of hearing loss-related issues, as well as libraries of files available for downloading. Members can exchange public messages with participants across the country. AOL organizes the forum by subject heading and also schedules online chat groups, where visitors can type

(SHHH) members, Association of Late-Deafened Adults (ALDA) members and such other persons as might be interested are invited to join us." "Beyonders" get together to meet each other in person at the SHHH and Cochlear Implant Club International conventions. To join Beyond Hearing, send a message to:

beyond-hearing-request@acpub.duke.edu

The body of the message should be: *subscribe*

The **SayWhatClub** "is an on-line group of late-deafened and hard of hearing and other interested folks who provide support and encouragement to each other through e-mail. Our goal is to provide a friendly, good-humored place to exchange conversation, information, advice, deep thoughts, humor, tall tales, and chit chat. It is our hope that members will get to know each other and develop an on-line 'community feeling.'" To join SWC, contact info@saywhatclub.com. The club's website is:

<http://webcom.com/~houtx/swc.html>.

Mental Health Counseling and Emergency Intervention

There are a number of mental health therapists in Massachusetts who specialize in working with Deaf, late-deafened, and severely hard of hearing people. Late-deafened people have often found mental health therapy very valuable, sometimes just to "talk it through, sort out feelings, and find coping strategies." Others have even found it life-saving when they were overwhelmed by the experience of losing their hearing.

For referral to specialized mental health therapists for the deaf:

- Contact MCDHH

For referral to emergency intervention programs:

- Contact DHILS programs across the state
- Contact MCDHH

Career Help

Many people who become deaf, especially when it is sudden, often have to make major changes to continue their careers, and may even have to find alternate employment. They may need special equipment, such as assistive devices, or may have to develop new communication strategies, change departments, perhaps even change their job objectives.

The Massachusetts Rehabilitation Commission (MRC) has specialized counselors for the deaf and also provides job training. (See full listing under Financial Assistance later in this chapter.) An MCDHH Case Manager can steer you to the appropriate resources.

Medical Help

There are several medical procedures which are available for some cases of late-deafness. You should consult an otologist or otolaryngologist to find out if these might be appropriate for you.

Treating Drug-Related (Ototoxic) Loss and Autoimmune Reactions

Most late-deafness is the result of damage to the inner ear and is not reversible through medication or surgery. Occasionally, sudden drops in hearing due to medication may be reversed by discontinuing the medication. And some losses due to autoimmune reactions have been successfully treated with steroids. In these cases, it's important to consult a specialist as quickly as possible. Even then, the prospects aren't bright.

Cochlear Implants (CIs)

For people who have severe to profound sensorineural losses (but intact auditory nerves) and do not get enough benefit from hearing aids, one option is the cochlear implant. In this surgery, an array of electrodes is implanted in the cochlea to stimulate the auditory nerve. A receiver is embedded in the mastoid bone behind the ear. Sound goes to a microphone worn on the head. It travels down a wire to a small box (the processor), which is worn on a belt or carried in a pocket or even in a bra and houses a small computer that converts the sound to electronic signals. These travel back up the wire to a transmitter held on the head by a magnet behind the ear, which sends it to the embedded receiver in the ear, from which it then travels to the electrode array in the inner ear where it stimulates the endings of the auditory nerve. At this writing, the FDA has approved implants from Cochlear Corporation and Advanced Bionics (the CLARION). Several other devices are undergoing trials.

A cochlear implant is not a hearing aid; it's far more complex and very expensive; the cost of the device, surgery, and follow-up rehabilitation and fitting cost around \$40,000, which may or may not be covered by your health insurance. Cochlear implants involve invasive surgery performed under a general anesthetic. However, the complication rate is low, around 10%, and serious complications are rare. Like any such surgery, implants should be considered carefully.

Results vary greatly and are not really predictable, but people who have been deafened for a relatively short time seem to be the best candidates. Hospitals that perform implants put candidates through a wide range of tests before surgery.

The incision takes about 4-6 weeks to heal, at which point the implant is connected to the processor, then turned on after programming. As with hearing aids, the sound that reaches the brain is far different from what we may have

been accustomed to, and the brain must “re-learn” how to hear. Most implantees report that initially, voices all sound like Donald Duck. “What if everyone, male and female, for the rest of my life, continues to sound like Donald with a speech impairment?” Paula Bartone-Bonillas remembers wondering. Getting the most from the implant involves fine-tuning the processor program and lots of work. Some implantees on Beyond Hearing report listening to the same song hundreds of times, gaining a little in understanding with each repetition. They may practice listening to books on tape and, in general, invest a great deal of time and effort into learning how to hear again. Many find the experience fun and exhilarating, marveling at each new sound.

A Different Perspective on Implants

Many individuals who are Deaf have absolutely no interest in nor need for a cochlear implant. To individuals who are born deaf or became deaf very early in life, deafness is simply part of their personal identity. As Deaf people, they have:

- a community of Deaf friends and family (as well as hearing) who readily communicate among themselves through American Sign Language, as well as using English when necessary and appropriate
- a multitude of accessible and available activities and services
- many auxiliary aids and services available today (the Telephone Relay Service, Interpreters, Translators CART service, captioning) as well as the growing number of people across the United States who are learning ASL every day, and
- a perfectly fine feeling of self-esteem and identity as Deaf persons; there is no need or desire to “become hearing.”

There are late deafened individuals who also share this feeling, especially after they have become acquainted with successful Deaf people and have acquired communication strategies that work for themselves. Some individuals who are late deafened will seek a cochlear implant and others will not.

Many users of current devices report some extremely impressive results, which bear fruit almost immediately. Nancy Delaney, a recent implantee, calls the decision to get an implant after almost 40 years of deafness caused by a childhood illness “the most courageous thing I have ever done in my life....but it certainly turned out well for me. I became a top performer during my second week of usage. I was using the phone by week #2 with limitations. I have progressed from there so that I can hear well without lip reading, even in moderate noise, I can hear music very well, use the phone with almost everyone.” Not everyone is such a star. Most people report steady progress over several years. Even those who receive the least benefit are able to hear environmental sounds, and find that it helps speechreading.

For more information:

- Advanced Bionics (makers of the CLARION)
800/678-2575 (voice)
800/678-3575 (TDD)
661/362-1500 (fax)
www.cochlearimplant.com
- Cochlear Corporation
800/523-5798 (voice/TDD)
www.cochlear.com
- Beyond Hearing list (see section above on Computer Groups) often has messages from people who have or are considering implants. Many people have posted “diaries” recounting their experiences after being “turned on.”
- Minuteman Cochlear Implant Club:
Contact: Larry Orloff
209 Rolling Ridge Road
Amherst, MA 01002
413/549-4108

Continued

- CI List: an Internet discussion group dealing specifically with cochlear implants. To subscribe, send a message to: listserv@yorku.ca with no subject line, and the following message in the body of the message (use your real name):
subscribe ci yourfirstname yourlastname

Auditory Brainstem Implants (ABIs)

At this writing, eight medical centers across the country are testing a device similar to a cochlear implant for use by people whose auditory nerves do not function. The *auditory brainstem implant* is particularly relevant for people with NF-2 (neurofibromatosis type 2, a hereditary condition in which acoustic tumors grow on the auditory nerve, which must be severed during life-saving surgery). The device is implanted directly onto the brainstem.

For more information:

- Cochlear Corp. (address in Cochlear Implant section above)
- House Ear Institute (where initial trials were held): www.hei.org
- NYU Dept. of Neurosurgery: www.med.nyu.edu/neurosurgery

Financial Assistance

Late deafness may mean a drop in income, as we are forced to change jobs and careers. With a pair of digital programmable hearing aids costing well over \$2,000 and cochlear implants running about \$40,000, most late-deafened people wonder if there is any possibility of receiving financial support. Although the IRS doesn't give a deduction to deaf people such as it gives to the blind, there are a number of sources of financial assistance for basic income, job-retraining, and for purchase of hearing aids and other technology.

For information about financial assistance, contact:

- MCDHH Dept. for Case Management Services
150 Mt. Vernon Street, Suite 550
Dorchester, MA 02125
617/740-1600 (voice)
617/740-1700 (TTY)
617/740-1699 (fax)
Email: andrea.koenig@state.ma.us
- Massachusetts Assistive Technology Partnership (MATP)
1295 Boylston St., Suite 310
Boston, MA 02215
617/355-7820
617/335-7301
617/335-6345 (fax)
Email: matp@matp.org
Electronic Bulletin Board: 800/950-6287 (in-state)
or 617/267-5027

Social Security

Late-deafened people who qualify can receive disability benefits through SSI (Supplemental Security Income) and SSDI (Social Security Disability Income).

SSI is a means test program based on financial need. Disabled individuals who are eligible for SSI benefits are those who have never worked or who have not earned the required amount of work credits paid into the social security system. In addition to receiving a monthly check, an eligible Massachusetts resident who is eligible for SSI is also eligible for Medicaid insurance. To qualify for SSI, you must meet certain financial eligibility criteria demonstrating general financial need.

SSDI pays a monthly check to people who have worked and paid into Social Security and have developed a disability. An individual who cannot return to his or her chosen work but can perform "gainful" work, is not

considered disabled. Recipients of SSDI automatically qualify for Medicare insurance after 24 months of receiving SSDI.

The application process for SSI and SSDI is complex and involves restrictions on the amount of income that can be earned in addition to the SSI or SSDI benefits.

For more information:

- Social Security Administration:
800/772-1213 (voice)
800/325-0778 (TTY) www.ssa.gov
- Contact MCDHH Case Management Dept.

Medicare Insurance

If you were a working individual who paid into the Social Security system, you may be eligible for Medicare. Medicare covers a wide range of medical benefits, but does not currently cover the cost of hearing aids, batteries, or anything else related to hearing aids. Hearing tests are covered but must be for “medical diagnosis” only, not for evaluations for hearing aid fitting. Cochlear implants are covered for individuals who meet certain criteria. A person eligible for SSDI is eligible for Medicare.

Medicaid Insurance (MassHealth)

If you qualify for SSI, you will also qualify for Medicaid insurance. Medicaid provides a range of hearing-related medical benefits, including purchase of hearing aids, coverage for minor repairs, and for audiological test. “Minimal” coverage is provided for cochlear implants.

CommonHealth

CommonHealth offers comprehensive health insurance coverage, either primary or to supplement other insurance policies. The policy, which is billed on a sliding scale, pays for medical and dental office visits, hospitalization,

medication, medical equipment, and many services not covered by most health insurance policies. Of particular importance to late-deafened adults, CommonHealth covers audiological/hearing exams and evaluations, earmolds, hearing aids, batteries, accessories, and repairs, and speech/language therapy.

New eligibility requirements went into effect July, 1997. You are eligible if you are a Massachusetts adult with a “permanent” disability who is ineligible for MassHealth and either:

- unemployed or employed for less than 40 hours/month (in which case there is a one-time deductible), or
- employed for more than 40 hrs./mo. (no deductible)

For more information:

- MassHealth Customer Service Center
800/841-2900 (voice)
800/497-4648 (TTY)

Massachusetts Rehabilitation Commission

The Vocational Rehabilitation Dept. of the Massachusetts Rehabilitation Commission (MRC) provides a wide range of benefits and services to late-deafened individuals who are eligible. MRC may cover the cost of assistive technology (hearing aids, TTYs, assistive listening systems, signal devices, etc.) when these are needed for employment. MRC also provides coverage for vocational training, re-training, driver training, and vehicle and home modifications for eligible individuals. For more information:

For more information:

- Mass. Rehabilitation Commission (MRC) has many offices across the state. To find your MRC Office and/or Rehabilitation Counselor for the Deaf, call information.

Bell Atlantic for adaptive telephone equipment

Deaf and hard of hearing people in Massachusetts can receive free TTYs, signaling devices, and amplifiers (see Chapter 5) through the Bell Atlantic Equipment Distribution Program. In addition, certified TTY users can apply for a discount on their local and long distance telephone service.

For more information:

- See Chapter 5
- Verizon Center for Customers with Disabilities
800/974-6006 (voice/TTY)

Veterans Administration

Financial assistance may be available to veterans whose hearing loss is related to in-service injury.

Title VII Part B

This is federal money made available to all of the DHILS programs and Independent Living Centers in Massachusetts for purchase of equipment and services to help people to maintain or achieve independence. The program can provide funding for assistive technology but there is generally a long waiting list. Title VII part B is not available to anyone who is eligible for services under the Massachusetts Rehabilitation Commission, and must be the last choice for funding.

Hear Now (HN)

Hear Now provides hearing aids and cochlear implants to eligible individuals with limited financial resources. Hear Now coordinates a national hearing aid bank and accepts hearing aid donations from people all over the country.

- Hear Now
6700 Washington Avenue South
Eden Prairie, MN 55344
800/648-HEAR (4327) (voice)
612/828-6946

Department of Public Health Hearing Aid Program for Children

Children up to 21 years of age are eligible if they meet financial guidelines.

- 250 Washington St., 4th Floor
Boston, MA 02108
Contact: Janet Farrell
617/624-5957 (voice), 617/624-5992 (TTY)
617/624-5990 (fax)

Division of Medical Assistance

Provides audiological and hearing aid evaluations for all people eligible for Medicaid.

- Medicaid Program
600 Washington Street
Boston, MA 02111
888/665-9993 (voice)
888/665-9997 (TTY)

Central Massachusetts Hearing Aid Loaner Bank

- UMass Memorial Medical Center,
Rehabilitation Group
15 Belmont St.
Worcester, MA 01605-2650
508/334-8700 (voice), 508/792-8727 (TTY)
508/792-8722, 8723 (fax)
Contact: Tina Coderre

■ Services for Senior Citizens

In addition to the support mentioned earlier in this chapter and the skills, options, and devices we speak of in later chapters, late-deafened seniors may want to check out the following resources:

Massachusetts Deaf Senior Citizens, Inc. (MDSC)

Provides social, cultural, recreational and educational activities for deaf seniors in the Commonwealth.

- Boston Center
St. Andrews Center for the Deaf
All Saints Parish, 1773 Beacon Street
Brookline, MA 02445
617/734-6078 (voice/TTY)
- Deaf Community Center, St. Anselm Parish
100 Landham Road
Sudbury, MA 01776
978/443-7764 (voice/TTY)
508/875-0354 (fax)

New England Home for the Deaf

A self-care facility for elderly deaf and deaf-blind people.

- 154 Water St.
Danvers, MA 01923
508/774-0445 (voice/TTY)

Continued

Gallaudet University Elderhostel Program for Deaf Senior Citizens

Offers accessible weeklong programs during the summer.

- Gallaudet University
University Conference Management
800 Florida Ave., NE
Washington, DC 20002
202/651-6000 (voice/TTY)
202/651-6107 (fax)

3. Communication Options

“Let me put my glasses on so I can hear you” may sound like a joke, but it’s not. When our ears fail us, we come to rely more on vision. In this chapter, we’ll talk a bit about some of the communication options open to late-deafened folk. In Chapters 5 and 6, we’ll discuss assistive technology and high- and low-tech auxiliary methods of communication. Each of us develops unique ways of dealing with communication situations. No single method is the answer for everyone. No single method works in every circumstance. The more tools you have, the easier the task becomes.

■ Speechreading (also known as lipreading)

If you recall my own story, I wasn’t even aware of my hearing loss until it had reached a fairly advanced stage. How was this possible? Apparently, I had unconsciously learned how to speechread — to use lip movement, facial expression, and body language to understand the spoken word. This is very common. Most people, even hearing people, already speechread to some extent, in noisy places, for example. I remember two girls in my fourth grade class who could carry on a conversation from opposite sides of the room without using their voices. Many people who lose their hearing at a young age are phenomenal speechreaders. Speechreading, however, certainly isn’t a cure-all. Many sounds look the same on the lips or are invisible; only about 30% of all speech can be identified by lip movement alone. So how do we get the other 70%?

- **Residual hearing:** I, for one, make good use of the little that is left of my hearing. Any little piece of the puzzle helps. It’s amazing how much we can derive from the smallest clue.
- **Context:** We can expect to hear certain words in certain situations. If I’m talking about Tiger Woods, the pro golfer, I might expect to hear the words *birdie*, *par*, *fairway*, *putt*, among others. If I’m in a

restaurant, I might expect the waitress to tell me about the soup and vegetable of the day, what salad dressings are available, or ask if I want my hamburger well done or medium rare. Knowing the topic lets us guess far more accurately. This is one reason why many of us have such a difficult time when a speaker changes the subject unexpectedly. You would not, for example, expect an archeology professor lecturing on the excavation of Troy to mention mutual funds or the Beatles.

- **Body language and facial expression:** Few people talk with a completely wooden expression. A raised eyebrow, a pout, a shake of the head all give us clues that we can use to help understand conversation.
- **Our intuitive knowledge of the language (“collocation”):** Some words keep company with other words. Having grown up in the hearing world, we are attuned to the grammar of the language, common phrases, the way words are assembled in English. We know, for example, that fairytales often begin *Once upon a time*, that people *set out* to do things, *make a dash* for their vehicles in a sudden downpour, that *events move toward a conclusion*, and *all’s well that ends well*. If we get even a few hints from speechreading, our brains can usually fill in the gaps. It’s a bit like doing crossword puzzles.

“Despite the fact that I am continually confronted by mumblers, I can usually communicate with anyone, using my speechreading skills and communication strategies — providing the other person has a pair of lips, a set of teeth, and does not speak in Swahili,” writes Barbara Liss Chertok of Florida, who lost her hearing at 21 as a result of a virus and now teaches speechreading in Maryland.

But, speechreading, especially if you are totally deaf and relying completely on visual cues, is very difficult and calls for intense concentration. Mustaches and beards, accents, sloppy speech habits, chewing gum and smoking are all

major challenges to speechreading, as are group situations and lectures delivered from a raised platform. At the end of the day or if I'm sick or tired, I sometimes don't have the energy to speechread with much success. It's hard work, so it's important to try to make it easier.

Remind the speaker — repeatedly if necessary — to face you when speaking. If possible, position yourself so that you are near the speaker and on the same level. To avoid shadows or light glare, light should be behind you or from the side. If, on the other hand, you're using signed English support to augment speechreading, you'll want to stand back a bit so that you have a wider visual field for all visual-gestural-behavioral clues. Ask the speaker to remove hands, pipe, gum or whatever may hide the lips. I even have a doctor who asks me to call a few days before my appointment so that he can trim his mustache!

How do you learn to speechread? You can try to teach yourself from books and videos, but it's far easier to take a class. You really need to be able to practice with a teacher, particularly if you don't have much (or any) residual hearing to provide additional clues. The Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH) can refer you to speechreading classes. You can also practice with friends or family. As with everything else, some people catch on faster than others. And some people are easier to speechread than others. If you don't like to guess unless the odds are very much in your favor, you may have difficulty; speechreading requires a lot of guessing and some leaps of imagination. Remember that in everyday conversation, you don't have to understand every word to be a successful speechreader.

Pro: All of us have some existing speechreading skill and even a few speechreading lessons may help significantly.

Con: Demands total concentration, since many sounds look the same on the lips. Very difficult in groups or if the speaker is far away, has facial hair, an accent, or doesn't move his or her lips.

■ American Sign Language (ASL)

Wherever there are deaf people, there has been and will always be a sign language because it is a **visual** language. American Sign Language has its roots in the early 1800's. In 1815, a young seminarian named Thomas Hopkins Gallaudet went to Europe to study teaching methods, funded by a group of Connecticut businessmen, with the intention of founding a school for the deaf in Hartford, Connecticut. In France, he studied French sign language with Abbé Sicard before returning to this country with Laurent Clerc, a deaf Frenchman. Clerc became the first teacher of the deaf in America. ASL has many borrowings from French sign language as a result, but it has its own idiomatic usage. The school Gallaudet and Clerc founded in Hartford became the first residential school for the deaf in the country, and continues to this day as the American School for the Deaf. Gallaudet's son, Edward Miner Gallaudet, went on to found what is now Gallaudet University in Washington, D.C., the only university for deaf students in the world.

American Sign Language is the primary language of the Deaf community in the U.S.; deaf users of ASL are thought to number about half a million people and the number of hearing people who become ASL fluent is growing. Some Deaf people use ASL exclusively, but most are bilingual and use English and ASL. ASL is not mime; it is a complete language with its own grammatical structure. Hand and body position, and orientation, as well as facial and body expression all occupy a place in the grammatical structure of ASL. ASL does not have a one-to-one relationship with English. Although it is distantly related to French Sign Language, it continues to evolve as do all languages. Like many other spoken languages, including Native American languages and indigenous languages in Africa and Australia, ASL has no written form for everyday use.

MCDHH updates an information sheet on Sign Language Classes. Many colleges, organizations, and adult education programs in Massachusetts offer courses in ASL. The

Massachusetts State Association for the Deaf (MSAD) also offers classes across the state. There are a number of books and videotapes available to supplement interactive classwork. Many hearing people take ASL classes because they have family members or friends who are deaf or



Annette Posell regularly uses a sign language interpreter for important meetings at her job at The Caption Center.

severely hard of hearing. Many other hearing people study ASL out of a fascination for the language. The best way to learn ASL is from a deaf person who is a fluent signer. As with learning any foreign language, you'll have to practice, practice, practice. If possible, try to attend some Deaf community functions. It's a very interesting and eye-opening experience to feel at first like **you** are in the minority, unable to easily communicate. Many Deaf individuals are bilingual or even tri-lingual, and will readily help the beginner with sign language.

Pro: A full language, with an inherent beauty. Fully visually accessible and enables use of ASL interpreters and Signed English Translitterators. Even a beginning knowledge of ASL will begin to facilitate participation in the Deaf community, many of whose Deaf members happily welcome people who are interested in learning their language. Many community events are interpreted and therefore visually accessible.

Con: Like any foreign language, may take years to learn fluently and requires lots of practice. Use of facial expression and body language sometimes difficult for English speakers. Its usefulness to you may depend somewhat on how many of your family, friends, and hearing associates know it or are willing to learn it.

For more information:

- **American Sign Language Class List**
MCDHH CATTS Department
617/740-1600 (voice)
616/740-1700 (TTY)
www.mass.gov/mcdhh
- **A Basic Course in American Sign Language** by Tom Humphries, Carol Padden & Terrence O'Rourke (T.J. Publishers, 1994); also available in Spanish and on videotape. Humphries and Padden have also written another book, **Learning American Sign Language**, also available with a video.
- **American Sign Language; a Comprehensive Dictionary** by Martin Sternberg (Harper & Row, 1981); also available in paperback condensed form and as a CD ROM
- **Books for Learning Sign Language** (NCID) Describes available books
- **Everyone Here Spoke Sign Language; Hereditary Deafness on Martha's Vineyard** by Nora Groce (Harvard Univ. Press, 1985)
- **Learning Sign Language: Audio Visual/Computer Programs** (NCID) Lists videotapes and computer programs for learning sign language
- **Signing Naturally**: a very popular curriculum; video and text

■ Fingerspelling

Every late deafened person should learn fingerspelling. It's a lot handier than using pen and paper when you are with other people who know it. Fingerspelling is taught in all sign language classes. American fingerspelling is a system of shapes made with a single hand (the

fingerspelling of Great Britain, Australia, and some former British Empire countries uses two hands) that correspond to the letters of the alphabet. Signers use fingerspelling for names and to spell out special words (scientific terms, names of corporations, such as *NYNEX*, for example). It's especially useful for unfamiliar names and addresses. Friends and family of late-deafened people often learn fingerspelling and find it extremely useful for indicating changes of subject in conversations or for supplementing speechreading for difficult words. Although learning the fingerspelled letters may be easy for some, reading and using fingerspelled words takes practice. Experienced signers can fingerspell with breathtaking speed.

See the next page for the Fingerspelling Alphabet.

Pro: Easier than carrying around a pad and paper. Extremely helpful for spelling out names and difficult words. Practiced users fingerspell very fast.

Con: Needs lots of practice to learn to use with speed. Receptive skills often lag behind.

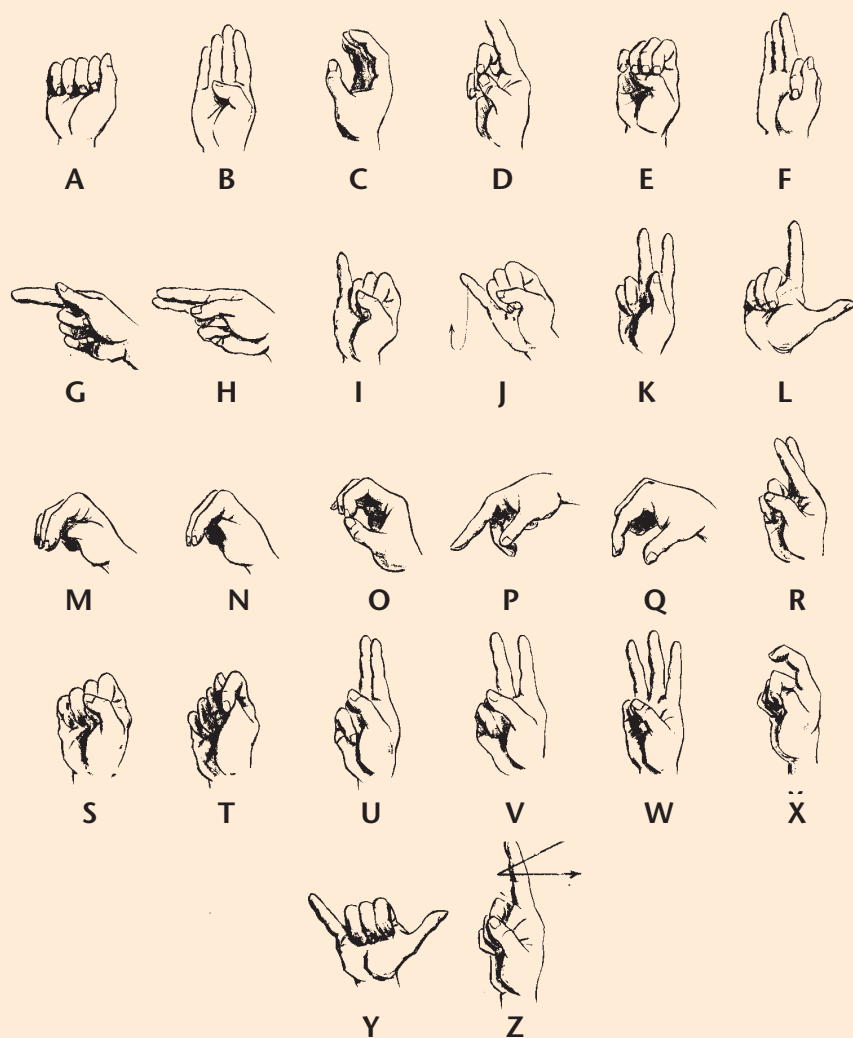
For more information:

- "Interactive Sign Language: Fingerspelling & Numbers," (Palatine, 1992) Computer program. Several shareware programs are also available.

Manually Coded English (MCE)

Various systems of manually coded English (MCE) have been created to provide deaf and severely hard of hearing users with visual support for speechreading English. Many late-deafened adults whose first language is English find signed English more easy to learn and use than ASL. They are attracted by the fact that they can speak and sign the primary English words in sentences simultaneously. Visual signs help the speechreader fill in the information for the

Fingerspelling Alphabet



“missing 70%” of speech sounds which cannot be seen on the lips.

There are several signed English systems that attempt to parallel spoken English with signs for speechreading support. All signed English systems, all forms of manually

coded English, use spoken English and signs simultaneously. All use ASL signs to some extent; some systems also use non-ASL, “invented” signs for many words. And some systems use invented signs for English markers, such as plurals, suffixes, past tense, pronouns, and so on. The two main terms you will hear are:

- **SEE** (Signing Exact English): SEE borrows many word-signs from ASL, uses some invented signs for words and also for grammatical markers (prefixes, suffixes, past tense, plural, etc.). Such a complex system is often very cumbersome to produce manually within the natural flow of speech and to process visually.
- **Forms of Signed English** use spoken English and English structures with ASL signs to parallel spoken (or mouthed) English. It tends to use fingerspelling considerably to “fill in” articles, sometimes pronouns, and other words. Some forms of Signed English also may use invented signs. Signed English is visually complex and hence somewhat cumbersome to produce, especially while simultaneously speaking. It is much harder to visually process than ASL.

Pro: Easier for some late-deafened and hearing people to learn than ASL since it uses English word order and grammar and relies less on facial expression. Possible to speak and sign simultaneously, thus making speechreading easier by supplying the “missing 70%” of speech sounds.

Con: Not a language. Cannot completely parallel English. Hard to maintain the flow and normal pace of the spoken language while simultaneously signing English. Because it uses the grammatical structure of English as its base, it is not structured (as ASL is) to accommodate visual reception and memory.

Another term that you may hear is Pidgin Sign English (PSE). PSE is a mix of signed English and ASL, in much the

same way that Creole mixes French and English, borrowing from both languages to facilitate communication between two speakers, neither of whom is fluent in the other's language. PSE generally employs some structures and idioms of ASL and uses some mouthed/spoken words of English. It is often the result when a Deaf person who is fluent in ASL and a hearing person who signs but is not fluent in ASL attempt to communicate. Each makes some accommodations to the other. Depending on the users, PSE can lean more towards "the ASL side" or more towards "the signed English side".

For more information:

- **The Signed English Starter** by Harry Bornstein and Karen Saulnier (Gallaudet); these authors have written a number of other books about Signed English and, with Lillian Hamilton, have edited a comprehensive dictionary of Signed English.

■ Cued Speech

Prof. R. Orin Cornett of Gallaudet University developed Cued Speech in 1966 to make the sounds of spoken language visible. For some people, cueing can be an aid to speechreading, helping clarify the sounds that look the same on the lips (such as B and M) sounds that aren't really visible on the lips (such as K and G), and vowel sounds.

Cued speech is relatively easy to learn. Eight handshapes used in seven different positions near the face signify different sounds. To cue, one must learn to think in terms of *sounds*. For example, there is no handshape for C; in English, it is either an S or K sound. This can be a difficult adjustment to make. Since Cued Speech is based on sound, you can cue any word you know how to pronounce. For some users, it's been very helpful in learning foreign languages.

Cueing hasn't really caught on. Cued Speech translitera-

tors, as they're called, are few and far between. Activity in the state seems to be centered at the Massachusetts Institute of Technology in Cambridge. A group in the Sensory Perception Laboratory there is developing an "Autocuer," a machine that can generate cues as someone speaks. Practice Cueing sessions, open to the public, meet once a month on campus, and Jeanie Krause, a graduate student in electrical engineering, has created a number of Web pages describing Cued Speech.

Pro: Easier to learn than ASL or Signed English. Presents a complete visual picture of the speech sounds of English, including information not provided by speechreading.

Con: Few people use it. Requires that we think of words phonemically (based on the sounds the letters make) rather than on how the words are written or spelled.

For more information:

- National Cued Speech Association
23970 Hermitage Road
Cleveland, OH 44122
800/459-3529 (voice/TTY)
- NCSA Information Services/Bookstore
CuedSpDisc@aol.com
- New England Cued Speech Services
<http://web7.mit.edu/CuedSpeech>

Which Should I Choose?

There is no "one size fits all" answer. However, many of us agree with the communication philosophy of the Association of Late-Deafened Adults: "whatever works."

All of us who have become deaf or acquired a severe hearing loss have spoken English as our primary language. Speech-reading is very important, and any technique that supplements speechreading is valuable. I personally think that anyone who is late-deafened or hard of hearing should first have some instruction and practice in speechreading and fingerspelling. Even if you don't become expert, you'll still find these skills increase your ability to understand the spoken word. Whenever we can pick up more clues to conversation, it makes the task of understanding easier.

From a practical point of view, you will probably want to learn whatever language is used by the people with whom you communicate most frequently. But even if that language is not ASL, you might still want to learn it (or signed English) to add a new dimension to your communication versatility. Many late-deafened people who have learned ASL enjoy participating in the social, political, and community activities of the Deaf community while maintaining important relationships with their family, friends, and co-workers in the hearing world. Many of them have found interesting Deaf friends and have been able to choose jobs in which they work with other Deaf and late-deafened people.

In addition, ASL automatically gives you a vocabulary for Signed English and you can easily make the switch to manually coded English. Fluency in ASL or signed English also gives you access to ASL interpreters or Signed English Translitterators, which can be a great convenience, since they are so widely used and relatively easily available.

When analyzing your communication needs, I think you have to ask yourself a few questions. First and foremost: will learning another skill help me?

- Look at your work situation. Do you work in a large office or are you a consultant working from home or in an office of your own? Do you spend time in a classroom situation, as a student or teacher? Do you travel? Attend meetings or lectures? Use the telephone for business? Would your co-workers be willing to learn a new language or skill to communicate better with you? Would the ability to use interpreters be useful?
- Look at your homelife: Would your family and friends be willing to learn a new language or skill in order to communicate better with you?
- What about your community? Are there any other people who use sign language or want to learn it?
- Do you have the time, resources, opportunity, and motivation to invest in learning new skills and/or languages?
- What kind of person are you? Are you outgoing or shy? Do you enjoy learning new skills and meeting new people?
- How good is your vision? Is speechreading really a possibility?
- Entertainment needs? Do you enjoy dining out? Partying? Attending plays and movies?

Many of us agree with the communication philosophy of the Association of Late-Deafened Adults: "whatever works."

I'm sure you can think of further questions, but this is a good start.

4. Communication Skills

As soon as you recover from the initial shock of becoming deaf, your first priority should be to start to deal with “The Communication Problem.” Because learning new ways to communicate is time-consuming, it’s a good idea to start by making the most of what you already have. You’ve probably always taken speaking and listening for granted. Now it’s time to take a closer look at communication strategies and do some problem solving. You’ll find that there are a number of factors that you can control.

■ Letting People Help You

One of the most difficult adjustments to make is to learn to ask people to work with us to optimize communication. Most people have no idea how to communicate with a deaf person. You’ll have to teach them. And when you’re finished, you’ll have to repeat what you said, and repeat it again. Changing speaking habits is very difficult. Asking people to change is also difficult. Have patience, ask politely, smile a little. Both of you benefit when your communication needs are met.

- Be honest. Tell people that you’re deaf. If you’re having trouble with the d-word, re-phrase it. I often feel that using it with certain people will upset them — I’m not quite sure how to react to stunned silence, embarrassment, or “I’m sorry” — so I sometimes just tell people that I have a profound hearing loss or am “very hard of hearing.” It doesn’t matter what you call it as long as you get your point across.
- Resist the urge to bluff. It’s far more difficult to tell people you’re deaf after listening to them speak for 15 minutes and not understanding a word. A little later in this chapter, we’ll discuss strategies to use when you don’t understand the speaker.
- If background noise is a problem, try to find a quiet corner with good lighting. If possible, turn off the television or radio or other source of noise.

- Carry a pad and pen, just in case you get stuck.
- Ask people to face you when they speak. Let them know that you won't hear them or even know that they're talking if they talk to your back or call to you from another room.
- Don't hesitate to ask speakers to remove gum or other objects from their mouths.
- Be polite but assertive about your communication needs. If you don't tell speakers how to speak to you, they won't know. And once they know, they may forget and have to be reminded. See the sidebar on page 73 for tips.

If Your Directions Aren't Getting Through

Every now and then, you'll meet someone who is rude or uncooperative. Try to find someone else with whom to speak. But if it happens frequently, it may have something to do with the way you're unconsciously behaving. Ask yourself: Am I being confrontational instead of reasonable? Impatient? Angry? There's a big difference between being assertive and being aggressive. Or maybe I'm not being assertive enough? Communication is a joint enterprise. Treat your "partner" with consideration.

■ Changing the Environment

Have you been wanting to re-decorate? Here's your chance. Start by analyzing where you normally sit during the day: at meals, when entertaining, when relaxing. There are a number of things you can do to improve the environment for communication.

Carpet and wall covering: Sound bounces off bare floors and walls, so if you have residual hearing, you may want to make changes in wall and floor covering. When I first stepped into my new condo, a converted school with 10 foot high ceilings, every word seemed to echo. Since unpacking, the situation has improved dramatically, but I could further improve it by adding a rug, draperies, wall-hangings and pictures.

- **Rearrange furniture:** It's important for you to be able to see the speaker's face without straining. Place your favorite seat so that the light isn't in your face and so that it's opposite where guests or family members usually sit. If you're speechreading, you'll want to sit fairly close to the speaker. If the speaker is signing, you'll want to sit a bit farther away, to widen your field of vision.
- **Position yourself** so that you don't have to crane your neck. If the speaker is sitting, sit. If the speaker is standing, stand. If the speaker is a Boston Celtic, find a ladder!
- **Make adjustments** as you go along at home, at work, and when visiting. People will understand if you close blinds in back of them so that you aren't looking into the sun, or move lamps, remove vases from tables, move a chair. Just explain what you're doing and why.

Dealing with Difficult Situations

In Chapter 8, Real Life Coping, we'll have suggestions for specific communication situations such as church, meetings, and lectures. Here, we'll just list some of the strategies you can use if you don't understand what someone says:

One of the simplest but most difficult things you can do is to get out of the "What?" habit. Sometimes, it takes the brain a fraction of a second to figure out just what the speaker has said. Most of us are guilty of asking "What?" the instant the words are spoken, only to figure out the meaning, in many cases, as the speaker begins to explain.

- **Rule #1:** Give the brain a split second before asking for an explanation of something you didn't hear.
- **Rule #2:** Don't say "What?," "Huh?," "I didn't get that," "Please repeat that," etc.

“What?” and its variations are a bit too open-ended to be useful. The speaker is left wondering exactly which part of the conversation you didn’t understand and tends to

repeat the entire sentence (or more), which may not be necessary. Try to be more specific when you request information. Sometimes, repeating back part of the sentence helps.

When the speaker says, “Janie graduated from Abbey Meadow Pre-School last Wednesday.”

Don’t say, “What?” Instead, try:

- “Who graduated?”
- “When did Janie graduate?”
- “What school was that?”

When you receive important information, be sure to confirm it. Most of us have shown up for appointments at the wrong time

or even the wrong day, misunderstood directions, and such. Everyone does this, not just late-deafened people, but it’s more likely to occur when you’re deaf. So, for example, tell the secretary, “Let me confirm this. I have an appointment with Dr. Jekyll next Tuesday, July 15th, at 10 a.m. And I shouldn’t eat or drink anything after midnight. Correct?”

Ask the speaker to re-phrase what he is saying or write down the key words or numbers. If you have residual hearing, you can ask for the correct spelling of a word or name you don’t understand, for example, “Was that *B* like in *Balcony* or *P* like in *Petunia*?” Be patient, with the speaker and **with yourself**. When you’re totally exhausted and having difficulty giving the speaker the concentration that is necessary, excuse yourself and take a short break. At social gatherings, give yourself permission to lean back and drop out. It isn’t bluffing, it isn’t surrendering your independence, it isn’t giving up the good fight. It’s sometimes a necessity to go to another room and relax or stay where you are and soak up the atmosphere from the background. If you’re with friends, just explain that you’re taking a break, that they should continue whatever they’re doing, and that you may ask for a summary or clarification later on. Ask them to hold any important questions or matters that require your participation until you’ve re-charged your batteries.

For Hearing People: How to Communicate with a Deaf Person or a Person with a Hearing Loss

- Make sure you have the person's attention before you speak.
- Face the deaf person. It's important for him or her to be able to see your face.
- Remove any objects from your mouth that might interfere with speechreading: gum, food, etc.
- Speak clearly and a bit more slowly than usual, if you normally speak quickly.
- Don't overemphasize lip movements. It will make speechreading more difficult, not easier.
- Don't shout. If the person has no hearing, it won't help. If the person has some residual hearing and wears hearing aids, it will only distort what you say.
- If the person doesn't understand what you have said, don't just repeat it. Re-phrase it.
- Try to give the person some indication when you change the subject.
- Make sure that only one person talks at a time.
- Recognize that speechreading and listening involve intense concentration for late-deafened people and can be very tiring.
- Ask the deaf person what you can do to make communication easier.

For more information:

- Contact MCDHH
- “Communication Tips for Adults with Hearing Loss” by Harriet Kaplan. NICD/ASHA publication
- **Communication Issues Related to Hearing Loss** by Samuel Trychin, 1993
- **Staying in Touch; Suggestions for Solving Communication Problems for Hard of Hearing People and Those Who Live or Work with Them** by Samuel Trychin, 1993

5. Assistive Technology

Everyone knows about hearing aids (although they might not know **much** about them); however few people know about some of the other devices that are available to late-deafened and hard of hearing people. In this chapter, we'll introduce you to some gizmos, gadgets, and technology that you might want to explore more fully. In the next chapter, we'll discuss auxiliary services that may also be useful.

Hearing Aids

Many people have some strange ideas about hearing aids. They equate hearing aids with glasses and think that all we have to do is put them on and our hearing will be miraculously restored. Unfortunately, that isn't the case. Although there have been some real advances in hearing aids in the last few years — miniaturization, digitization, computerization, programmable features such as methods to constantly sample environmental sounds and adjust the volume accordingly, and frequency filters to minimize unwanted background “noise” — the essential problem of hearing aids remains: they can't distinguish between sounds that we don't want to hear and sounds that we do want to hear. And unlike ears, they aren't omnidirectional, so it's difficult to locate sound. Nevertheless, if you have some residual hearing, you will probably want to see if there is a hearing aid that will benefit you, if only to let you monitor the sound of your own voice and hear environmental sounds.

Styles of Aids

There are six main styles of hearing aids:

- **Behind the Ear (BTE) aids:** consist of an earmold that fits into the ear canal and most of the outer ear, connected by a short plastic tube to an aid that sits behind the ear. Most common for people with severe to profound losses.
- **In the Ear (ITE) aids:** the entire hearing aid fits

inside the outer ear. Although there are a few powerful models, most are for moderate rather than severe to profound losses.

- **In the Canal (ITC) aids:** fit completely inside the ear canal. Mainly for mild to moderate losses.
- **Completely in the Canal (CIC) aids:** fit deep in the ear canal and removed with a stem of wire
- **Body aids:** these have cords going into earmolds, but the hearing aid is contained in a unit the size of a pack of cigarettes which is hung around the neck or worn in the chest area. Used by a small number of profoundly deaf people and also for children who might lose or damage more delicate aids.
- **CROS (Contralateral Routing of Signal) aids:** for people who have no hearing in one ear and usable hearing in the other; resembles a behind the ear aid, but contains a wireless microphone and transmitter, or a cord to route sound from the deaf ear to the better ear.
- **Bone Conduction Aids:** Some hearing aids use bone conduction of sound vibration. The hearing instrument is connected to a headband that has a small thumbnail sized oscillator (vibrator) positioned against the bones of the skull to transmit vibrations to the listener.

Audiologists usually recommend getting hearing aids for both ears.

How to Buy Hearing Aids

When you lose all or part of your hearing, your first consultation should be with a doctor specializing in hearing loss (an otologist, otolaryngologist, or ENT doctor). You need to find out if your loss is caused by something that is medically or surgically treatable. As part of the examination, the doctor will send you to an audi-

ologist, who will test your hearing. Your *audiogram* shows what frequencies of sound you are able to hear at what volumes; other supplementary audiological tests show how well you understand (*discriminate*) those speech sounds under various conditions. If you have no residual hearing, the process ends right there. A hearing aid will do nothing for you.

If aids are a possibility, your next destination is the office of a hearing aid dispenser or dispensing audiologist. This is the person with whom you will work to select, modify, and fit the appropriate hearing aid or aids to accommodate the special characteristics of your hearing loss. The dispenser will also introduce you to the use of the aids and instruct you in their care and feeding. Select a hearing aid dispenser with care since this is the person with whom you will work very closely. To find a hearing aid dispenser, get a referral from the doctor, a friend who wears aids, a clinic, or a reputable organization. On September 4, 1998, Governor Paul Cellucci signed Chapter 321 of the Acts of 1998, which calls for the establishment of a Board of Registration for Hearing Instrument Specialists. With the passage of this new law, Massachusetts joins 48 other states that have a state licensing process for hearing aid dispensers. The new hearing aid law sets minimum standards for entry into the field and also sets enforcement standards for violations of practice, ethics, or unlicensed practice. It also states that effective July 1, 2000, no person in the Commonwealth may practice dispensing of hearing aids unless licensed as an audiologist or by the Board of Hearing Instrument Specialists. You should understand the different credentials of individuals who dispense hearing aids:

- A dispensing Audiologist has a master's or doctoral degree. Audiologists specialize in the diagnosis, evaluation, and management of hearing loss and have extensive training in hearing loss and rehabilitation. In addition, they have passed a certification exam and hold a credential from the American Speech Language and Hearing Association (ASHA)

- A Board Certified Hearing Instrument Specialist has training in fitting and dispensing hearing aids, has taken an exam and holds a credential from the National Board for Certification in Hearing Instrument Sciences.
- Some individuals who sell hearing aids hold no credential. Such individuals may or may not have had appropriate training through courses and/or apprenticeships.

In addition to considering the qualifications of the hearing aid dispenser, you want to buy your aids from someone who:

- carries a number of different brands and models
- will spend time answering your questions and coaching you in the use of the aids
- will give you a reasonable trial period to use the aids, at least 30 days and possibly more, and has a reasonable return policy if you find the aids are of little use or if you want to try another model
- will be able to offer you a loaner should your aid need to be repaired
- is familiar with ALD (assistive listening devices, which we'll discuss later in this chapter) and knows how they work with certain hearing aid options

Fitting hearing aids is both art and science, particularly for a severe to profound loss. This is because hearing loss is a very complex business. If it were only necessary to crank up the volume, then it would be a simple matter, and Uncle Al, who always yells at you, would be very easy to hear. 'Tain't so. For one thing, the amount of amplification usually has to be different at different frequencies, since most of us don't have a flat loss. Second, many people with sensorineural hearing loss cannot tolerate loud noises and can hear comfortably only within a very

narrow range of amplification. But the main roadblock is that hearing loss consists of more than a simple need for amplification. The way the brain interprets sound is the other half of the picture, and much of it remains a mystery. Two people with the exact same audiogram can have very different comprehension abilities. One may be able to *discriminate* speech sounds with a fair degree of accuracy. The other person, with poor *discrimination*, will hear noise rather than words.

A good hearing aid dispenser has a lot of tricks up his or her sleeve: venting the earmold, making it from different materials, changing the diameter of the eartube or earhook, and making adjustments to the way the hearing aid amplifies sound. All this is to say that ears do not always behave exactly the way tests predict.


Richard Rosenthal, author of **The Hearing Loss Handbook**, published in 1975 (and not to be confused with the book of the same title published more recently by **Consumer Reports**), tells of how he was interviewing a professor of otolaryngology (an ear, nose and throat specialist) at a New York medical center. The surgeon, noticing that Rosenthal was straining to hear him, snapped, "Why the hell don't you get a hearing aid?" "I replied that a whole host of doctors and audiologists had unanimously and recently told me that I did not need an aid or could not benefit from one," wrote Rosenthal. "'Horsefeathers [sic],' he replied. 'Forget them. Get a hearing aid.' I did. It helped immediately," reported Rosenthal.

Telecoils (aka T-Switch or T-Coil)

Never buy a hearing aid that doesn't have a telecoil. This is a bit of electronic circuitry (a small spool or coil of wire) that lets the aid pick up electromagnetic energy from another telecoil found in a source such as a hearing aid-compatible telephone receiver, and convert

it back to amplified sound. Since 1989, every corded telephone sold in this country has been required to be “hearing aid (telecoil) compatible.” Telecoils vary greatly in effectiveness, like the old rabbit ears on televisions. You should ask your hearing aid dealer to make sure that the aids you buy have powerful telecoils. To activate the telecoil, adjust the switch on your aid to the T setting; you’ll probably have to increase the volume setting on your aid, too. Position the external telecoil (the one in the telephone handset, for example) close to the internal telecoil of the hearing aid until you receive a clear signal. The sound may be somewhat different from what you hear on the microphone setting. Using the telecoil not only prevents the feedback (whistling) that you may get using the microphone setting; it also eliminates background noise. The telecoil is also extremely important because it lets you use some of the assistive listening devices and systems we talk about later in this chapter. Some aids that do not have telecoils can be retrofitted with them, for a fee—if there is room available inside the instrument to do so.

Direct Audio Input (DAI)

Some hearing aids come with, or can be retrofitted with, a *direct audio input to the hearing aid’s amplifier by means of a multipin cable, (DAI) jack, or coupled via a DAI shoe or boot*. Look for this symbol . DAI lets the aid make a direct connection to any audio output, such as a radio, microphone, tape recorder, television, or assistive listening device, bypassing the hearing aid microphone. Using DAI eliminates background noise, since the aid connects directly to the desired sound source, an ideal situation for noisy environments, or for people who work in an area with ambient EMF (electromagnetic fields) such as medical professionals where the telecoil cannot be used.

Hearing Aids: A Recipe for Success

1. Wear the aids for several hours per day in a quiet environment to adjust to the new sound and to feel comfortable with the earmolds and manipulating the aids: inserting and removing them, adjusting the controls, etc.
2. Wear them in conversation with one or two people in a quiet setting, watching television, reading to yourself.
3. Wear them indoors in some minor noise: in the kitchen using an electric can opener, while running a fan in the bedroom, etc..
4. Try wearing them outside in a quiet area, then move to a noisier area. Wear them while driving, walking around a mall, in small groups.
5. Try them in the classroom or a large room, at church, talking to several people.
6. Experiment with adjusting volume and, if your aid is a programmable one, try changing programs in different situations.
7. Use the aid's telecoil (T-switch) with the telephone and see if it helps you hear on the phone. You'll have to experiment with the position of the telephone handset on your ear, since the location of the telecoil varies greatly from model to model.
8. Wear them in a noisy restaurant or a party.

Adjusting to Aids

If you've never worn hearing aids before, you're in for a period of adjustment. Attitude is everything. If you don't want them to work, don't even bother to try them. That's what happened when I tried my first aid, loaned to me by a university clinic. I didn't even have an earmold, just a universal earplug. I put it on, turned on a Joan Baez recording, listened for a minute, announced that I *still* couldn't hear the words of the song, and took the aid off. In my defense, no one had told me that listening to music was not the way to test out a hearing aid. But it

could have made me hear like the Magical Helper of the folktale who could hear grass grow; and I still would have refused to wear it and would have found fault with it. I just wasn't emotionally ready for hearing aids and it was years before I would be.

People often think that they can put on the aids, walk out of the office, and hear perfectly again. The sad reality is that once you've gotten the aids, your work has just begun. Here are some tips for adjusting to hearing aids.

Start by wearing them several hours a day and build up. Earmolds can be very irritating. If yours is, go back to your hearing aid dispenser and ask to have the earmold or tube adjusted. If you experience an allergic reaction to the material of the mold, ask for a different mold made from hypoallergenic material.

Try the aids in different situations. (See sidebar on previous page.)

Keep a record of your experiences so you can tell the dispenser how you've done when you return for a follow-up visit.

Have patience. Your brain needs time to learn to interpret the new sounds it hears. You need time to become comfortable with the aids. Recent research indicates this takes about 12 weeks.

For further information:

- Contact MCDHH
- "ABC's of Hearing Aids" SHHH Information Series #101
- **A Consumer Handbook on Hearing Loss and Hearing Aids: A Bridge to Hearing** edited by Richard Carmen Auricle Ink Publishers 1998
www.hearingproblems.com

- “A Consumer’s Guide for Purchasing a Hearing Aid,” SHHH Information Series #102
- “All About the New Generation of Hearing Aids” by Cynthia Compton et al. The Clerc Center.
- “Getting the Most Out of Your Hearing Aids.” By C. Everett Koop, M.D. Video, open-captioned. (SHHH)
- “Hearing Aids,” AARP Product Report, Vol. 1 No. 4
- **The Hearing Aid Handbook** by Donna Wayner. Gallaudet Univ. Press
- “How to Buy a Hearing Aid,” **Consumer Reports**, Nov., 1992
- “The New Hearing Aids and You” by Cynthia Compton et al. The Clerc Center.
- “The ‘T’ Switch; Some Tips for Effective Use” by L.B. Beck (SHHH Publication)
- “The Telecoil: Plugging into Sound.” SHHH and Johns Hopkins Center for Hearing and Balance. Video, open-captioned (SHHH)

Vibrotactile Body- Worn Aids

Tactile aids provide a non-invasive alternative for late-deafened adults who are unable or unwilling to get cochlear implants and who seek support for visual speechreading. They can work in conjunction with hearing aids (if used) to provide an impressive array of speech information not available from speechreading alone. These aids consist of a series of small vibrators mounted on a band that is worn across the chest or on the wrist or forearm. Sound is processed and sent to the vibrators. Tactile aids can alert the user to environmental sounds and help monitor speech production. They can also work in conjunction with speechreading and hearing aids to

“fill in the gaps.” Users can learn to identify a great deal of speech information from the location, intensity, and duration of the vibration pattern, for example, the explosive feeling of the P sound, the difference between the unvoiced F and voiced V, and the S at the end of a word.

For further information:

- Audiological Engineering Corporation in Somerville 617/623-5562 (voice); 617/666-5228 (fax); is the main player in the international vibrotactile aid market.
- Hearing Rehabilitation Foundation (HRF). President Geoff Plant is a leading authority on tactile aids. E-Mail: HearF@aol.com

■ Assistive Listening Devices and Systems (ALDS)

In addition to hearing aids, there are a number of assistive listening devices and systems on the market that amplify sound and may be of help to people who have some residual hearing. They can be very helpful in situations where hearing aids don't do the job well: in noisy places (such as restaurants), in large group meetings (churches, senior center presentations), classes, business meetings, etc. In the next pages, we'll survey some of these.

The objective of all ALDS is the same: to increase the intelligibility and clarity of speech by putting the microphone closer to the speaker's mouth or sound source, and by decreasing background noise. Audiologists speak of this as increasing the *signal-to-noise ratio*.

ALDS are useful for personal listening and also for group situations. They consist of an external microphone or a direct cable to the sound source, a transmitter, and a receiver. There are a variety of listening attachments: People with mild hearing losses can use them with headphones. People with severe and profound hearing losses

often can use these with a *neck loop* or *silhouette* that works with the hearing aid's telecoil, or with a *direct audio input (DAI)* wire that connects directly with the hearing aid's amplifier. Cochlear Implant processor patchcords are also available. There are several types of devices:

- **Hardwired Devices:** These are used in one-on-one situations. For example, a person with a hearing aid might connect a microphone directly into his aid's DAI. A more common type looks like a Walkman and can be used with earphones or a neckloop or DAI, if the audio source doesn't have its own jack. The transmitter box contains an amplifier, battery and volume control, and either a built-in microphone or a jack for an external one.

FM Systems: These broadcast sound over designated FM frequencies to individual receivers. For portable use, the transmitter and receiver can be battery-operated; each is approximately the size of a deck of cards. For large meetings, an AC powered transmitter is often used which connects to the existing public address sound system or mixer in a meeting room with multiple microphones in use. Anyone with an FM receiver that is tuned to the appropriate frequency can listen to the sound source through headphones, a neckloop, cochlear implant patch cord, or DAI. The receivers can be placed in a pocket or hung around the neck. Some new hearing aids even have built-in FM receivers. The systems are highly portable and can be very effective. On the down side, they tend to pick up interference from other broadcasts.

- **Infrared (IR) Systems:** These are very similar to FM, but transmit sound using infrared light waves from a public address system or microphone through an infrared light emitter to the receiver. Infrared systems are favored for use in theaters. Although they don't have problems with interference, as do FM systems, the cannot be used out-

doors in bright sunlight, and the receiver must have an unobstructed “view” of the transmitter. They, too, can be used with neckloops, direct audio input, and other listening attachments.

- **Audio Loop Systems:** These are permanent or temporary installations in a room and are popular for small group meetings because they are portable and relatively inexpensive. A wire runs around the periphery of the room and attaches to an amplifier into which the microphone is also plugged. The amplifier converts the sound into electrical signals and feeds them through the wire, creating a magnetic field within the loop. Listeners inside the loop can pick up the sound using the telecoils of their hearing aids, or cochlear implant, or via a small audio Induction Loop Receiver and listening attachment. Sound quality varies widely; there may be interference from fluorescent lighting, and there can be dead spots in the magnetic field. Loops can be assembled inexpensively from parts from an electronics store. I know several people who have loops in their homes and even their cars.

For meetings, you can use your own hardwired device or FM system, with a conference microphone in the middle of the table. Or you can pass the transmitter/microphone around the table. Neither solution is ideal, but they’re an improvement over trying to speechread using only hearing aids. A personal FM system can also work quite well in a classroom or lecture type situation, where the microphone can be taped to the lectern or the speaker can put the transmitter in a pocket and use a lapel microphone connected to that FM transmitter.

Accommodations such as churches and synagogues may have ALDs on hand, though they may not have the type of receiver and listening attachment that you prefer. For example, many churches and synagogues have FM receivers with earbuds for their members to use. A single FM transmitter at the podium or connected to their

existing public address system serves all of them. Other facilities, particularly movie theaters and concert halls, prefer infrared systems. Some of these use headphones; some use a stethoscope-type receiver that hangs under the chin. Different FM systems transmit on different frequencies and not all FM receivers are multi-channel or field-tunable, but **most** infrared receivers will work with any infrared emitter. If you purchase one of your own for home use, you can also take it with you to the theater. When purchasing any ALD, make sure that you arrange for a trial period.

Photo by Jonathan O'Dell



Trained Hearing Dogs are identified by a special harness and/or special orange collar.

■ Alerting Devices and Signaling Systems (ADSS) (Audible, Visual and Tactile)

In an issue of the now defunct magazine **Life After Deafness**, publisher Gayle McCullough tells how her husband locked himself out late one night and spent hours in the cold trying to get her attention. All of us have tales of this sort to tell, some funny (at least in retrospect), some sad, some tragic. Luckily, simple solutions are available in the electronics department, as well as not-so-simple solutions in the four-footed, wet nose department (see the next section). Deaf people have used signaling devices for years: lights that flash when the doorbell or phone rings or a baby cries; vibrating alarm clocks and “bed-shakers” to wake the sleeping, even ingenious Rube Goldberg-type setups that use a fan as a signal. Some of these systems are quite simple; for example, you can buy an inexpensive module that plugs into the wall at one end and into a telephone jack and a lamp at the other. When the phone rings, the light flashes. Or you can get a single unit that flashes different sequences depending on the source of the sound (doorbell, telephone, crying baby, for

example). There are Dick Tracy style watches that vibrate when a transmitter “hears” a sound, and pagers that vibrate and show a short message or code when someone phones. If you have some residual hearing, you may want to try out adjustable audible ringers with your telephones. There are also special smoke alarms with very loud horns and flashing strobes. There are alerting devices just for one specific need, and signaling systems which enable you to add components as needed to outfit your entire home and be informed of environmental sounds.

Service Dogs

Not all assistive devices are inanimate. Every morning, Creature, a shaggy little dog of uncertain ancestry, jumps into bed to wake my deaf friend Barbara at the ringing of the alarm. As they drive to work, Creature, now formally dressed with her orange leash, alerts Barbara to the sirens of any approaching emergency vehicles. Creature has become a fixture at the large high tech company where Barbara works as a technical writer. After greeting the security guard, she makes herself comfortable on her bed under Barbara’s desk. The dog responds to ringing telephones and also alerts Barbara when someone comes into her cubicle or calls her name. At home, Barbara feels more secure knowing that Creature will let her know if someone rings her doorbell or knocks on the door, if the kettle is whistling, or if the smoke alarm goes off.

Creature is a graduate of the hearing dog training program at Red Acre Farm in Stow, which was phased out some years ago. But there are many other programs that train assistance dogs, and there are also private trainers. If you’re an experienced dog trainer, you may be able to train your own dog to respond to a number of signals, but it takes a great deal of work, time, and effort. I tried to get my own dog to alert me to a ringing telephone, but she’s from the classic Alfred E. Neuman “What, Me Worry?” school of thought. She does, however, tell me when someone is at the door, as do most dogs I know,

with or without training. And, although she sleeps happily through fireworks and thunderstorms, on the two occasions when the low battery warning on my smoke alarm was beeping, she kept me awake all night wondering why a terrified 60-lb. dog was trying to sit on top of my head. Hearing ear dogs, much like seeing eye dogs, are by law permitted to accompany their owners into places of public accommodation.

■ Telephone Devices

For late-deafened people, telephones are the ultimate nemesis. In our hearing pasts, they played a very large role, something to which we hardly gave a thought. Now, they've become instruments of torture. We can't hear them ring; we can't hear telephone conversations. And we live in a world that is increasingly turning to cellular phones and voicemail. We can address this situation from a number of angles.

Hearing Aid (Telecoil) Compatibility of Telephones

All phones sold in this country must now be "hearing aid (telecoil) compatible," able to work with a hearing aid telecoil. A telecoil is not the same thing as an amplifier.

Telephone (Hearing and Speech) Amplifiers

For people with some residual hearing, there are a number of telephone amplifiers on the market. Some are portable, and strap onto the handset. Some are small

For more information:

- **Chelsea; A Signal Dog** by Paul Ogden (Little, Brown)
- The Clerc Center Information sheet
- "Hearing Dogs" by Ellen Terryberry (SHHH Information Series #256)

The body of the message should be: *subscribe*

boxes that can be connected between the handset and the telephone base. Some are replacement handsets with volume controls, while others are desk phones with built-in controls in the base to increase either incoming speech or outgoing voice. Some will adjust the tone and pitch as well, to enhance clarity and understanding. All of these should also work in conjunction with your hearing aid's telecoil, but there are often electronic compatibility problems between amplifiers and telephones, so you'll have to test them.

For more information:

- "Alerting and Communication Devices for Hearing Impaired People: What's Available Now" by Loraine DiPietro et al. (The Clerc Center /ASHA)
- "Assistive Devices: Doorways to Independence" by Cynthia Compton (book and video) (Gallaudet) available from SHHH
- "Assistive Listening Devices; A Consumer-Oriented Summary" by Cynthia Compton and Fred Brandt (Gallaudet University)
- "Beyond the Hearing Aid with Assistive Devices," SHHH Information Series #251
- **Do-It-Yourself Listening and Signaling Devices for People with Hearing Impairment** by William Paschell, 1988
- "Signaling and Assistive Listening Devices for Hearing-Impaired People" (Alexander Graham Bell Association for the Deaf)

Phone equipment distribution

Massachusetts residents who are deaf or hard of hearing can qualify for a program administered by Verizon (and developed by MCDHH, the Massachusetts Commission for the Blind, the Massachusetts Rehabilitation Commission, the Department of Public Utilities, and representatives from the user community) that distributes special telephone equipment to people with disabilities at no charge (if your income is over \$50,000, there is a small charge). A late-deafened, deaf or hard of hearing person may choose either a TTY and two signaling devices or an amplifier and two signalers. To receive equipment, you must receive certification from MCDHH.

For more information and an application, call:

- **Verizon – New England**
280 Locke Drive, 4th Floor, Marlboro, MA 01752
800/974-6006 (voice/TTY)
- **MCDHH**
617/740-1600 (voice)
617/740-1700 (TTY)
Contact: Mary Macone

■ TTY (Text Telephone)

Those of us who can't hear on the telephone use a TTY, an acronym/abbreviation for a *teletypewriter*. A TTY is a small, table-top unit with a keyboard, a one-line screen for visual display of text, and an acoustic coupler, into which you place the telephone handset. (On some models, you can use "direct connect" and plug your telephone line directly into the TTY). Some TTYs have small, built-in printers. Many have an auto-answer mode that works like an answering machine and can save and print messages from another TTY user if you don't answer the call yourself. TTYs are sometimes called TDDs (Telecommunications Devices for the Deaf). More recently, the federal government tried unsuccessfully to popularize the acronym TT for (text telephone). Whatever you call them, they were invented in the 1960s by physicist Robert Weitbrecht, using a converted newsroom teletypewriter machine, an enormous contraption.

Two TTY users can type messages to each other over the phone lines. If it sounds a lot like computer "chat," it is. Because even champion typists type much more slowly

Some TTY Terms

GA	Go Ahead (It's your turn)
SK	Stop Keying (Goodbye)
HD	Hold
TMW	Tomorrow
MTG	Meeting
PLS	Please
Q	Used instead of ? to indicate question
U	You
UR	Your
CUZ	Because
MSG	Message

If you speak with someone frequently, you tend to invent your own private set of abbreviations.

than we speak and the transmission rate of a TTY is limited, TTY conversations are very slow, so we use many abbreviations. But you don't have to be a whiz-bang typist to use a TTY. Typing with one finger works just fine with some practice. Most telephone companies give a discount to TTY users, since calls take longer.

One of the main shortcomings of using a TTY is that both parties must have them or use the Telephone Relay Service. (More on the Relay Service in Chapter 6). Can you use your computer to communicate with a TTY? Yes and no. TTYs "speak" in "baudot" while computers use "ASCII" code. Unless the TTY has an ASCII option (most new ones do), you can't communicate directly with a standard computer modem, and dual purpose modems are relatively slow and quite expensive. Even if the TTY can communicate in ASCII, your modem may not be

able to slow down to the speed at which the ASCII TTY operates. If you want to use a computer modem to receive TTY calls automatically, you'll have to leave the computer on all the time. Otherwise, by the time you flick the switch and the computer wakes up, the caller will have long since disconnected. MCDHH has a list of manufacturers of computer/TTY software.

For more information:

- What You Should Know About TDDs by Dr. Diane Castle (NTID)

■ Modem-to-Modem Communication

One solution to this dilemma, assuming that both of you have computers with modems, is to use them for realtime chatting. Modem to modem chatting is very similar to TTY chatting. You and the caller take turns typing messages to each other; these show up on your monitor. After making an appointment to chat, both users turn on their computers and start “Instant Messenger” or a similar program. Once you learn how to use the software, chatting is a breeze. The keyboard is larger and better and the screen is obviously on a completely different level than the small one-line display of a TTY. You don’t need expensive computer equipment to chat. The slowest, most antiquated personal computer with a (gasp!) 300-baud modem and monochrome display will do the trick. Modem to modem chatting isn’t limited by computer or modem speed; it’s limited by typing speed. If you want to communicate with a friend or relative who can’t afford a TTY, it may be possible to outfit the other person with an old PC. You’ll not only be able to chat, you’ll also be able to send files back and forth, but that’s another story.

■ Optional Telephone Services

In the last few years, Bell Atlantic has added a number of optional services that can be useful to late-deafened people. More services are being developed all the time, as your local phone company thinks of new and innovative ways to part you from your money.

Distinctive Ring Service

Bell Atlantic calls it Ringmate; in other parts of the country, it’s known by different names. It allows you to have several different numbers on a single phone line, each with its own ringing pattern. For example, I have two Ringmate numbers (plus my main number). The main number is my voice number. When someone calls it, my signaling light flashes a series of single long rings; if I don’t answer the phone, these calls go to my answering

machine. My second number is a fax number, which the signaler indicates by a series of two short rings. My third number is a TTY number, which the signaler indicates by a series of short-long-short flashes. That's all Ringmate does by itself, used with a signaling light. I've heard of people who find this sufficient and manually switch on the appropriate device when the signal flashes. In order to route the call to the proper device automatically, however, you'll need a special unit. Newer fax machines often come with a built-in router. Otherwise, you'll have to buy one separately. For me, this has been an excellent investment since I don't have to be home to receive messages on the TTY, or faxes. And my answering machine can also take a voice message.

Caller I.D.

Another product, Caller I.D. uses a small box connected to the telephone line (or a telephone that supports Caller I.D.) to display the number and sometimes the name of the caller as soon as the phone has rung once. When I first tried this several years ago at my summer place in Vermont, I gave up in despair after a few weeks. Except for local calls, almost every call displayed an "Out of Area" or "Unknown" message. When I moved recently, I ordered the service and have been pleasantly surprised by its improvement. It's made the task of returning calls much easier, since I now usually don't have to go through an involved rigmarole to hear the caller's number (I'll have more to say about this in Chapter 8) or get someone to transcribe a voice message from my answering machine to get the number.

Call Answering Service

This service replaces your voice answering machine by creating one or more mailboxes for you. For people like myself who live alone without full-time answering machine transcription service (otherwise known as a spouse or partner), it's a great convenience, since you can ask the

Relay operator to call your mailbox and retrieve your messages.

For more information:

- Call the Verizon Center for Customers with Disabilities at 1 (800) 974-6006 (voice/TTY).

■ Televisions

For some reason, many of us find it very difficult to speechread television. That might be understandable for dramatic programs, where the camera angle is rarely full-face, but there aren't even many television news reporters whom I seem able to speechread with ease.

Infrared Systems

Inexpensive systems, similar to the ones we discussed in the section on assistive listening devices and systems are a popular choice for use with televisions. You've probably seen them for sale in department and electronics stores. They come with a unit that connects to the TV and sits on top of it and a rather heavy headset that the user wears. Ads herald them as "marriage savers": "now, your spouse can sleep while you watch the Late, Late, Late Show." If one of these works for you, fine. Don't give up the search, though, if it doesn't. A more powerful, but expensive, unit may fit the bill. And remember: you can use an infrared receiver with any infrared transmitter, including the ones used by many movie theaters and concert halls.



Photo credit: Off-screen print courtesy of The Caption Center in Boston. Copyright 1990 Paramount Pictures Corporation. All rights reserved.

Star Trek: The Next Generation is one of many captioned programs available on television to deaf and hard of hearing people.

Closed Captioning

Closed captioning has made many television programs and movies and even video clips on computer software (like Microsoft Encarta) accessible to millions of deaf and hard of hearing people. In this technique, the audio part of the broadcast is displayed as printed text, usually in two- or three-line subtitles (such as those used in foreign language films), at the top or bottom of the screen.

In 1972, the WGBH Caption Center in Boston captioned the first nationally broadcast television program, supported by funding from the Department of Health, Education and Welfare. The program? Julia Child's *The French Chef*.

Captioning and Universal Design

Captioning is a prime example of how intelligent design features intended for one audience can, in fact, find favor with other segments of the population. Captions have been found convenient and useful by people who aren't deaf or hard of hearing: children learning to read, people learning English as a second language, television viewers who don't want to bother others in the room, patrons in noisy bars and restaurants who wish to follow the action on widescreen televisions and monitors. This is a good example of how universal design, an effort to develop products that can be used by people with a wide variety of abilities in many different circumstances, can benefit everyone.

For further information:

- "Getting the Words on the Screen: A Guide for Low-Cost Captioning" (Soundoff! Productions, 1996) open-captioned video and manual (available through SHHH)
- **TV Listening: Some Do-It-Yourself Suggestions for Hard of Hearing People** (SHHH)
- The Caption Center Website: www.boston.com/wgbh/captioncenter
- National Center for Accessible media (MAGpie) NCAM <http://www.wgbh.org/wgbh/pages/ncam>

Since that time, captioned telecasts have increased dramatically. During most of that period, it was necessary to have a small “decoder” to display closed captions. However, since July, 1993, every television set manufactured or sold in this country with a screen 13 inches or larger has been required by law to have built-in circuitry to display closed captions. Different manufacturers use slightly different variations, but in general, you turn captioning on and off using the remote control or through the setup menu.

Most major release rental videos are now closed captioned, and many oldies are also being distributed with captions. Look for the closed captioning symbols on the back of the box.



■ At the Theater

Under Title III of the Americans with Disabilities Act (ADA, about which we'll have more to say in Chapter 8), theaters (movie and live performance) are required to provide assistive listening devices and auxiliary aids and services (like captions, interpreters for their deaf and hard of hearing customers. The ADA doesn't specify what kind of ALDS must be provided; most theaters have either FM or infrared systems. Several companies and theater corporations are experimenting with new ways to approach the problem, such as installing displays for captions on the back of seats. Expect to see interesting developments in the near future.

In addition, the Massachusetts State Association for the Deaf (MSAD) has recently been working with several movie theaters in the Boston area to show recent movies in open captioned form about once a month. Open captioned subtitles look much the same as closed captioning, but require no special equipment to display. There are a number of ASL-interpreted productions in the

area each year, in downtown Boston theaters as well as at theaters across the state.

For more information:

- See **Deaf Community News**, the publication of MSAD.
Massachusetts State Association of the Deaf (MSAD)
220 Main St.
Malden, MA 02148
781/388-9115 (TTY), 781/388-9114 (voice)
781/388-9015 (fax)
- National Center for Accessible Media NCAM
<http://www.wgbh.org/wgbh/pages/ncam/>
- www.tripod.org (open captioned films in theaters)
- Caption Media Program (loans open-captioned movies free of charge).
1447 East Main St.
Spartanburg, S.C. 29307
800/237-6819 (TTY), 800/237-6213 (voice)
800/538-5636 (fax)
Email: infor@cfv.org

■ Auxiliary Methods of Communication

TTY and Relay calls take at least four times longer than regular voice calls. For this reason, many late-deafened people encourage their callers to use other methods of communication when messages don't demand immediate attention or a lot of back and forth discussion. Only a TTY, Relay call, or computer chat provide the give and take of live conversation, but many communications lend themselves to simpler forms that can be read and answered at our convenience if we use fax or email.

Fax

When I bought my first fax machine, I had no idea what I'd do with it. Now, I can't imagine what I'd do without it. When I walk in the door, the first things I check are my TTY and my fax machine to see if anyone has left a message for me. Many of the people I do business with have fax machines, and prefer to receive faxes from me rather than Relayed calls.

Most new computers come with fax modem cards. They're excellent for sending word processing files you've prepared on your computer. But they're less ideal for receiving faxes. The computer must be turned on to receive a fax and you'll need a separate scanner if you want to send photos or graphics, even a fancy letterhead. Many fax software programs are also difficult to use, or quirky. Good stand-alone fax machines are fairly inexpensive; prices of machines that use regular paper have now fallen under \$150, and several manufacturers sell multi-function machines targeted at the home office that serve as fax machines, computer printers, and copiers.

E-mail

For those of us with computers, electronic mail (e-mail) has become a way of life. I can leave a message for someone at midnight and have my reply as soon as the recipient checks her e-mail in the morning. Many of my editors prefer that I send stories by e-mail, and I find that I'm doing more and more of my rental business this way. For me, the advantages are many. I can compose messages and pick up mail during a spare minute or a break. I need not worry about interrupting someone at work or waiting for long distance rates to go down in the evening. I can keep a record of all correspondence and don't need an intermediary such as a Relay operator to help me with a call. Nor do I have to find an envelope and stamp or drop off my letter in a mailbox. All I do is hit the Send button. And I can send copies to all my friends if I'm so inclined.

To start using email, you'll need a computer, modem, and communication software. You don't have to be an expert typist, although you'll probably improve your speed as you use e-mail. Although I began my infamous e-mail career on local electronic bulletin boards (BBS's) and still log on one daily, most people use an online service such as America Online (AOL) or Compuserve. When you sign up for these, you'll receive software and a temporary password, with directions for logging on. In fact, if you have a computer, you've probably already received several pounds of AOL software in the mail or tucked into computer magazines. The services charge a monthly rate for a given number of hours of usage. In addition to e-mail, you'll be able to join conferences, such as the ones we discussed in Chapter 2, get weather reports, surf the Internet, receive stock quotes, and access many other options. New users often get carried away by the Chat Rooms, where they can "talk" online to others with similar interests and problems. Experienced users know that nothing runs through usage time as quickly as chatting, which is, of course, why the online services promote it.

"The world will be a better place when everyone has e-mail."

— Anonymous

In the last few years, hundreds of small Internet Service Providers (ISPs) have sprung up across the country to challenge the online services. Many of these services offer an e-mail address and unlimited time each month for exchanging messages and visiting Websites. Like the online services, your monthly fee also includes free storage for a Web page, if you'd like to create one. Surfing the Web using an ISP is usually far faster than on an online service, but you won't be able to access the many special interest groups that many people find of great interest on AOL and Compuserve. When shopping for an ISP, look at more than price:

- Check to make sure that the service has local access numbers in your area so that you don't have to make a long distance call to log on.

- Try to find out how responsive Tech Support is.
- See if the service offers a trial membership so you can test drive it.
- Ask if free software is included with your membership and if there is an initial setup charge.

6. Auxiliary Services

There are, in addition, a number of auxiliary services that can help in many of the communication situations that arise in business, school, and everyday life. Unlike assistive listening devices, and systems which are useless for people with no residual hearing, these services are equally accessible to all late-deafened and hard of hearing folk.

■ The Telephone Relay Service (TRS)

Using the Telephone Relay Service, a TTY-user can communicate with people who use voice telephones. A TRS operator “relays” the call, acting as an intermediary. I make very few TTY to TTY calls because few of my friends own the devices. But I use my TTY many times each day to make Relay calls. By dialing an 800 number (or now dialing just 711 within Massachusetts) with my TTY, I connect with a relay operator who dials my call. I speak directly to the other party (this is called VCO, Voice Carry Over); or I could type and the operator would voice my end of the conversation. When the person I am calling replies, the operator types what is said so I can read it on the screen of my TTY.

Using the Relay is slow, but it’s the only way I can successfully call someone who uses a voice telephone. I have other means of communication, but none where I can get

Photo by Karen Rockow



Helen Fleming uses Voice Carry Over through the Massachusetts Telephone Relay Service. She speaks through the regular voice phone and reads what the hearing/talking caller is saying on the TTY.

an instant answer or answer questions myself directly over the telephone. Unless one of my hearing employees or friends is available, I use the Relay for all my telephone calls, even ordering pizza. People sometimes hang up because they're unfamiliar with Relay and think the call is a solicitation, but on the whole, most of the people I call are intrigued by it and cooperate fully. Relay operators are trained to type whatever they hear over the line and are obligated to adhere to a strict code of confidentiality. Someday speech recognition software might automatically transcribe the voice part of the conversation.

Relay Numbers

- **For local, in-state toll, and long distance calls:**

Mass Relay	1 800 439-2370 (TTY) 1 800 439-0183 (voice)or simply dial 711(voice/TTY)
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- **For long distance calls:**

AT&T	1-800 439-2370 (TTY) 1-800 855-2881 (voice)
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MCI National Relay	1-800 947-8642 (voice) 1-800 688-4889 (TTY)
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SPRINT National Relay 1-800 877-8973 (voice/TTY)

Each state has its own Relay service, as do the larger long distance companies. Most telephone companies recognize that TTY calls are more time-consuming than voice calls and offer TTY users a discount. For more information:

For more information:

- **Telecommunications Relay Service (SHHH)**

Interpreters and Translators

Although speechreading and assistive listening devices and systems may work well in a one-to-one or small group situation, understanding becomes far more difficult and stressful in situations where getting every word accurately is important, and for lectures, classes, and speeches where the speaker is far away or on a raised platform, or simply doesn't speak clearly. For many years, late-deafened, severely hard of hearing, and Deaf people have been using Translators, Interpreters and, more recently, CART - Communication Access Realtime Translation - to translate or interpret the spoken word into a form of visual communication. Interpreters, Translators, and CART Reporters are highly skilled professionals who are paid by the hour at market rates. In most cases, they are paid by agencies, services, and businesses where the services are used.

CART Service and/or Interpreters and Translators can be used in practically any setting where spoken communication needs to be visually accessible, for example, in adult education, college, and elementary or high school classes; lectures; court; meetings with attorneys, accountants, doctors, insurance brokers, construction contractors, car dealers, investment consultants; in senior centers; rallies on the Common; theater performances; marriage counseling; on-the-job training; performance meetings with the boss; weddings and wedding receptions; funerals — virtually wherever access to communication is needed.

MCDHH Interpreter/CART Referral Service

**617/740-1600 (voice)
617/740-1700 (TTY)
8:45 a.m. - 5:00 p.m., M-F**

For medical, mental health and legal emergencies only:

**800/249-9949 (voice/TTY)
24 hours a day, 7 days a week**

CART Service

Communication Access Realtime Translation (CART) Service is one type of “interpretation” or translation which is often the choice of deaf or hard of hearing individuals who are fluent in reading English, have not chosen to learn sign language, and who usually also have understandable spoken language. CART Service provides a visual text with nearly instantaneous translation of the spoken word. The CART Reporter types the speaker’s words on a stenotype machine, which is connected to a notebook computer that translates the stenographic code into English. The deaf person can read the results in plain English text translation on the screen of the notebook computer, or on a larger monitor plugged into it. For larger group events, the text can be displayed on a large video screen or projected on a wall screen.

CART Reporters are professional court reporters with very good “realtime typing skill” and special training about deafness and how to provide translation service for deaf people. Because they “type” in a phonetic shorthand, CART Reporters can type at speeds of 225 words per minute, which is average speaking pace. By comparison, most Telephone Relay Service operators are only required to type at 45-60 words per minute, which is as fast as data

How Do I Arrange for CART Service?

- To request a demonstration of CART Service, call MCDHH.
- To obtain CART service, the agency or individual who is paying for the service should call the MCDHH’s Interpreter/CART Referral Service.

617/740-1600 (voice)
617/740-1700 (TTY)
8:45 a.m. - 5:00 p.m., M-F

Since demand for this service has been rising steeply, you should call well in advance. If you want notes from the session, you may be able to arrange in advance with the CART reporter to get a diskette. Plan to provide the reporter with a list of names of people who will be speaking, technical terms, acronyms and other words that should be entered into the software dictionary. During long meetings, remember to schedule a break; CART reporting is very intensive work. Sometimes at very long events, two CART Reporters work together, taking turns.

can be transmitted on a TTY.

CART Service is an excellent choice for group meetings; even hearing people appreciate the convenience of not having to strain to catch poorly articulated or amplified words. For

conferences, CART/Video Projection Service, which projects the captions above or below an image of the speaker, is ideal, since it lets the listener read the transcript and speechread the speaker simultaneously.

Photo by Brenda Schertz



CART Service is Jane Sokol Shulman's choice for communication access in large government business meetings. The CART Reporter (in the foreground) "keys in" to the steno machine what is being said; the computer translates the spoken language into print; and Jane reads the text on the laptop screen.

■ Interpreters/Transliterators

For late-deafened adults who are able to use ASL or signed English, or who are competent speechreaders, using an interpreter or an oral transliterator may be an excellent way to handle communications at important meetings and conferences. MCDHH has an Interpreter Referral Service and is active in the approval process for interpreters.

For our purposes, there are several different types of Interpreter:

- **ASL Interpreters** interpret spoken English into American Sign Language and interpret ASL into spoken English. One must be fluent in ASL to use an ASL Interpreter.

- **Signed English Transliterators** translate spoken English of the hearing person into mouthed (no voice used) English supported by signed English for the deaf individual. They also translate the signed English and spoken English of the deaf person into standard spoken English. One must learn signed English or ASL to use this type of interpreter effectively, although good speechreaders sometimes find it useful to watch a Signed English Transliterators in a meeting.
- **Oral Transliterators** soundlessly and very clearly mouth the words of the speakers. Extensive training enables them to present a very visually clear model of what is being spoken for the person with the hearing loss to receive, paraphrasing when necessary for words that are not visible on the lips. The Oral Translators may also voice the message and intent of the speech and mouth movements of the person who is deaf or hard of hearing, so that the hearing person can understand. The deaf individual must have good speechreading ability to take advantage of oral transliteration.

How to request an Interpreter

To request an interpreter, call the Interpreter/CART Referral Service at MCDHH:

617/740-1600 (voice)
617/740-1700 (TTY)
8:45 a.m. - 5:00 p.m., M-F

Specify the location and time of the event, what the topic will be, preferred mode of communication, who will attend the event, and names of preferred interpreters, if you wish. Some interpreters have expertise in specialized areas, for example, medical, court, or legal settings. Try to make arrangements well in advance, since the demand for interpreters is greater than the supply.

Interpreters, Transliterators and CART Reporters are all professionals who have had special training and hold certification. They have a strict code of professional ethics

Continued

and are sworn to confidentiality about any and all information about their assignments and the communications exchanged during those assignments.

For Hearing People: How to use an interpreter

- Speak at your natural pace. The interpreter must hear a complete thought before signing it.
- Look at the deaf person and speak directly to him or her. Never say, “tell him” or “tell her.”
- Stand or sit opposite the deaf person and next to the interpreter, if possible.
- For meetings in large rooms, try to reserve seats in the front for people who will be using the interpreter, so they can see more clearly.
- Remember that the deaf person must be able to see the interpreter’s hands and upper body. Make sure the interpreter is visible whenever slides or movies are shown.

For more information:

- Contact MCDHH

■ Note-takers and Computer-Assisted Notetaking (CAN) (and C Print)

When CART is unavailable or too expensive, you may be able to turn to note-takers. These can be professionals or volunteer classmates or co-workers. They can take notes by hand, or they can type them on a computer, to be read from the screen (this is known as CAN, Computer-Assisted Notetaking). Because note-takers don’t use shorthand, it isn’t possible for them to provide verbatim transcription; instead, they summarize the proceedings,

much as you would if you could hear and were taking notes yourself. CPrint, a hybrid of CAN and shorthand abbreviations, will not provide verbatim accuracy as CART does but may provide more information than CAN's Key points.

For more information:

- Contact the National Technical Institute for the Deaf (NTID) for a listing of reprints available from the NTID Tutor/Notetaker Program. They also sell special multi-carbon paper sets. The Alexander Graham Bell Association publishes a training guide for notetakers and a manager's guide.
- "Try Computer-Assisted Notetaking" by Barbara Virvan (SHHH)

7. Helping Yourself

In addition to seeking help from groups, services, and technology, we must also take the initiative to help ourselves. We must become teachers, students, and advocates. One can almost hear John Houseman of Smith Barney advertisement fame intoning, "Late deafness has its responsibilities."

Become assertive

Learn to ask for accommodations and assistance. Tell people how they can help you communicate better. This is a classic example of "If you don't ask, you don't get." Easily said, I know. Asking for help is not The American Way. But deafness is invisible. You cannot expect people to change the way they communicate unless they know you're deaf, and you cannot expect them to know that you're deaf unless you tell them. This is one of the instances when support groups can be very valuable. If you feel uncomfortable being assertive, speak to others and find out their tricks of the trade. Some groups even have assertiveness training sessions where you can get the opportunity to role-play and test out different approaches. The more you practice assertiveness, the more you refine your technique and the easier it becomes. Jane Sokol Shulman tells of meeting with her professors each semester to tell them about her hearing loss (she was severely hard of hearing at the time) and explain what they could do to help her follow lectures and class discussions. "By going through the process of speaking to my professors, by using the words *hearing impaired*...I got used to the words, I got used to the ideas. At first, of course, I cringed every time I had 'the talk,' but after a while it got to the point where I could do it calmly."

Remember that few hearing people know much about deafness. They may, in fact, have many misconceptions about the best way to help. You will have to teach people about deafness and what they can do to make communication easier.

■ Make your environment communication friendly

We've already discussed some of the things you can do to optimize conditions for spoken communication in your home and place of work: They bear repeating:

- If you have residual hearing, use carpets and drapes to improve acoustics
- Re-position furniture and lighting to come to the aid of speechreading
- Install signaling devices
- Make use of TTYs, telephone relay services, and other technology

■ Carry a pad and pen

When all else fails, you can always resort to a pad and pen, but you'll have to carry them with you. There is nothing worse than hunting for a scrap of paper in the middle of a conversation. Or you might want to invest in a small handheld computer.

■ Relax

Don't attempt the impossible. When you're deaf, spoken communication can become an exhausting and stressful process. Try to plan your days to include time for rest and relaxation. Schedule important appointments when you know you'll be fresh. Most important of all, give yourself permission to drop out.

A few years ago, when my dog graduated from obedience class, I decided it was a good excuse to celebrate, and invited quite a few friends to drop by afterwards for cake and coffee. My dog loves company and is very lively and sociable, often to the point of becoming a nuisance. But that night, having performed during class and been very excited over company for half an hour, she decided that she'd had enough and crawled under an end table in

a corner and went to sleep. Every now and then, when I've overextended myself and following conversation becomes too much of a burden, I have to stop and ask myself, "Why aren't you as smart about this as your dog?" There are times when we just cannot muster the energy and concentration necessary to follow spoken communication. Don't keep beating your head against the wall. Make your apologies (probably not as effective as wagging your tail, but it's the best we can do) and fade into the background, or move to a quiet corner for a while.

■ Become an advocate

If you're looking for battles to wage or Good Works to do, you've come to the right place. The Deaf, late-deafened, and hard of hearing population has made great strides in the past few years, but we're still at the beginning of the road. Because hearing loss is invisible and isn't life-threatening, it's easy for legislators, corporations, employers, and providers of services to overlook issues related to it. There are many causes to campaign for and each of us has favorites:

- **Accessibility:** We'll discuss the Americans with Disabilities Act and its requirements in the next chapter. You can lobby for CART and interpreter services, note-takers, assistive listening devices in public places.
- **Captioning:** Many late-deafened people have found that their letters and phone calls have brought about more hours of captioned telecasts. Don't forget to send a note of thanks to the station (and even to the program sponsor) when it sees the light.
- **State Legislation:** Right now, there are several critical pieces of legislation at the State House: a proposal for an increase in the budget for purchase of independent living services for people who are

late-deafened and hard of hearing; a bill that would require hearing aid dispensers to be registered, and another to require them to have adequate training, pass a test, provide trial periods, etc.; a bill requiring hearing screening for newborns. Your support can make a difference. This book has been produced through funds allocated to the Massachusetts Commission for the Deaf and Hard of Hearing as a result of advocacy to the legislature by members of the Association of Late-Deafened Adults. There will continue to be many possibilities for action in the political arena.

- **Insurance Coverage:** Many health insurance plans now cover the cost of cochlear implants. But very few cover the cost of routine audiograms and hear-ing aids. Again, your voice can make a difference.

Spread the word:

We've spoken about this before, but it bears repetition. Once people know more about deafness, many will go the extra mile for you. In a recent message on the Beyond Hearing online discussion group (see Chapter 2), Muriel Bartholomew recalled her daughter's wedding. (Muriel was totally deaf at the time and had not yet received a cochlear implant.): "I was absolutely stunned...when the bride and groom took their vows FACING the congregation while the pastor's back faced the people. It was a total surprise to

When Life Hands You Lemons, Bake Bread???

Life is full of small annoyances that sometimes only need to be brought to the attention of organizations and manufacturers. Recently, for example, a member of Self Help for Hard of Hearing People (SHHH) in Montana received a Black & Decker breadmaker as a gift. It arrived with recipes, instructions, and a videotape that showed how to use the machine. But the videotape was uncaptioned and therefore useless to the woman. She wrote to the company and requested a captioned video, or, alternately, a transcript of the tape. Black and Decker arranged for a transcript from the production company in Canada and she had it within two weeks.

me and I was able to read the young couples' lips as they said their vows." A small point, perhaps, but a kindness that gives that warm, fuzzy feeling.

■ **Try new modes of communication**

Take a class in speechreading and/or sign language. Practice with friends or at meetings and social events. Learn the benefits of using a TTY and the Telephone Relay Service (TRS), fax machines, and email.

■ **Work with your hearing aids and assistive listening devices**

If you use hearing aids or assistive listening devices, help them to help you. Practice with them, try different settings. Learn what works and what doesn't. Consult with your audiologist or hearing aid dispenser to optimize them for your particular needs. It's an ongoing process.

■ **Join a support group, meet new friends**

As we've seen, members of ALDA and SHHH frequently come to think of the groups as "family." They're brought together by hearing loss, but stay together because they find other interesting people in the groups. Each of these support groups has an annual national conference, another way to have a vacation and enjoy relaxed communication, make and meet friends. The same holds true for computer forums and lists. Last year at the SHHH national convention in Orlando, I met a number of members of the Beyond Hearing list (we call ourselves BHers, or Beyonders) with whom I'd been exchanging email for over a year. And at this year's Cochlear Implant Club International (CICI) convention in Sturbridge, I'll meet Beyonders from as far away as Australia, as well as a recent implantee from the North Shore with whom I've been exchanging messages for over three years.

Find new activities and interests

You'll be surprised at the number of activities that don't require hearing. Hearing isn't necessary for most sports (although you'll probably miss out on trash talk on the basketball court). Try walking or hiking, cycling, jogging, swimming, riding, boating (no one can hear above the noise of the motor, anyway), golfing, skating, water- and snow skiing. And there are any number of other activities to try: writing, reading, painting, antiquing, pottery, knitting, weaving, cooking/baking, sewing, gardening, going to museums, keeping up written or computer correspondence, surfing the Net, yoga, meditation, the list is endless.

And, if you learn sign language, you'll discover that many recreational activities are interpreted: theater events, sometimes musicals, museum lectures, etc.

If you're curious about Deaf culture, contact a DHILS Program (an Independent Living Program, providing services for Deaf, late-deafened, and hard of hearing people). You may meet other people who share your interests and will help you become fluent in sign language.

You may find, as many others have, that deafness makes you get off the treadmill and think about what really interests you, what is really important to you. Once you've figured that out, just do it, as the ad says.

Perform a reality check

If you seem to be constantly in conflict with people, it may be time to analyze what's happening. For one thing, it's very easy to cross the line from assertive to aggressive. For another, it's easy to let your anger over your deafness, if that's still an issue, taint completely unrelated episodes or activities. I once knew a woman who had begun to lose her hearing as a teenager, became late-deafened as an adult, and was now working as a librarian. She was active

in the Deaf community, well respected by her co-workers, and was fluent in ASL. But she still seemed enraged at her parents, who had insisted when she first began to lose her hearing that she remain in a mainstream classroom.

She had never been able to resolve that issue with them and seemed to need to create conflicts with others so that she could vent her righteous indignation. When she travelled with her hearing dog, she left his identifying leash behind, then walked boldly into the ladies' room with him, apparently looking for a confrontation (and often finding one). Because he was a service dog, he was legally entitled to this privilege, but no one could tell that he was a service dog. She became furious whenever a hearing person spoke to her while her back was turned, but refused to tell people that she was deaf and how best to communicate with her. A number of us listened in dismay to her stories of run-ins with various strangers. We tried to tell her that she couldn't expect people to be mindreaders, that they would be happy to meet her halfway but that she had to take the initiative and teach them. "I spend all day teaching," she replied. "I don't want to have anything to do with it when I'm on my own free time." I've always been sorry that we weren't able to help this very bright and talented woman understand that certain chores come with the territory and that she was behaving in an unreasonable and manipulative manner. Learning to be deaf can be difficult.

Living well with deafness isn't much different from living well with anything else. A great deal depends on attitude. Is the cup half empty or half full? Do you think that most people are eager to oblige or are they self-absorbed? Is deafness a challenge or a burden? I've found that our expectations are usually fulfilled. I've been touched many times by the kindness of even the most casual acquaintances: the doctor who trims his mustache before my appointments; the associates who volunteer to take notes for me at meetings; the people who send me clippings; the friends who make sure I can follow the conversation at the dinner table.

8. Real Life Coping

Each of us develops a personal “style” for handling difficult communication situations, but it’s helpful to learn how others cope. In this chapter, we’ll discuss some common scenarios.

■ Explaining Deafness to Hearing People

One of your first tasks will be to develop a short spiel to explain your deafness to hearing people with whom you come into contact. You’ll want to give people some guidelines for talking to you, for example, “I’m deaf and I speechread. I need you to speak more slowly, face me, and please don’t yell.” Some people will also need an explanation of the nature of your hearing loss. This is fairly easy if you’re deaf as a post. If you have some residual hearing and wear hearing aids, it becomes more difficult. After several years of explaining to people that my aids do not correct my hearing the same way my glasses correct my vision, that I hear them speaking but it’s gibberish, I’ve recently switched to a briefer version. I now tell people that I just don’t hear the consonants in most of their words. Since few people have thought about consonants since the third grade, it definitely makes them pause and think.

■ Telephones Revisited

We’ve already discussed some of the telephone devices and workarounds you can use: TTYs, Relay service, telephone amplifiers, signaling devices, fax machines, e-mail, etc. For those of you who haven’t completely abandoned the voice telephone, or sometimes need to understand voice messages on an answering machine, here are a few additional tips.

Answering Machines

Put directions for calling back via Relay in an answering machine message: For my cottage rental business, I’ve had little success with this, but my outgoing message is

already overly long and includes many, many directions. You may have more luck on a strictly personal phone line; I've found that most business callers know nothing about either TTYs or Relay services and aren't about to learn from a 30-second answering machine message. Since many of my business calls are from out of state, callers are also understandably reluctant to make yet another long distance call to reach me using a contraption they couldn't distinguish from a head of lettuce.

So what do you do when someone leaves a voice message on your answering machine? While we're all waiting around for speech recognition software to come of age and put our answering machines out of their misery, the best solution is probably to use the telephone company's Call Answering service, if it's available in your area and will work with your phone system. You can then have a Relay operator call your mailbox and transcribe the message for you. If that isn't a possibility and if no hearing members of the household are present, you'll have to get creative. My personal solution has been to stick with the older type of answering machine that still records a message on a standard size cassette. I then pop out the cassette, put it in a handheld tape recorder, and either play it over the relay to a hearing friend, or grab a pen and pad, and wander through my building looking for a neighbor who can play secretary for me. This has its limitations; I once found myself at midnight asking a total stranger I met in our parking lot to listen to a message. It turned out to be a call telling me that an aunt had died, and it was a tossup which of us was more upset. The next day, before leaving for New York for the funeral, I arranged to get a separate Ringmate number for the TTY so I could leave it on auto-answer mode to take emergency messages.

Distinguishing Numbers and Letters

Although I hate to do it, if the voice phone rings when I'm home, I'll take the call and pray a little. Since these days, I have trouble distinguishing a Yes from a No over the phone, my current technique is to call back using the

Relay. The problem then becomes how to get the caller's number if it doesn't register on my Caller I.D. unit or if I'm at a different extension. Although the only numbers I can understand with a fair degree of accuracy are 0 and 7 (since they both have two syllables), I've had good luck asking people to count out each digit, for example, if the first digit is a 4, to say "1-2-3-4." I may not be able to understand the numbers themselves, but I can tell when the counting stops. You can do the same thing with letters, or make up your own alphabet:

"Was that *B* like in *Butterfly*, *A* like in *Appendix*, *R* like in *Rhinoceros*, and *T* like in *Tiddlywinks*?" Make up your own custom alphabet with friends, using words of two or more syllables that are unique.

A is for Artichoke

B is for Balderdash

C is for Crustacean

D is for Dynamite

E is for Elephant

F is for Fiddlesticks

G is for Galaxy, etc.

Shopping

"Where are the canned peaches?" can become a major research project when you're deaf. The best method of getting an answer may be to ask the employee to show you the number of the aisle by holding up the appropriate number of fingers. Some supermarket employees will welcome the respite from stacking boxes of corn flakes and lead you to the peaches. Or you can carry a pad. At the register, you can usually position yourself so that you can see the total. Another strategy is to pay with large bills and not worry too much about hearing the precise amount. This calls for a bit more trust than I can muster.

In supermarkets and other large stores, it's important not to forget that the sales people are there to help you, though they sometimes lose sight of the fact. Remind them.

Doctor's Office and Hospital

Strangely, the medical profession seems too often unable to make adjustments to deal intelligently with people who are deaf. Why does the nurse always call your name to summon you? Unless you want to spend the entire time you're in the waiting room in a state of high alert, you'll have to explain that you're deaf and tell the receptionist that you won't hear anyone call your name. It's then their problem, but you can help things along by sitting where you can easily see and be seen by the nurse.

If you need an interpreter or CART service to communicate at your medical appointment, be prepared for a battle. Unless you're dealing with a large hospital, most doctors are reluctant to foot the bill for interpreter services, although they have considerable responsibility to do so under the Americans with Disabilities Act.

For more information:

- MCDHH has published a 12 page "mini-guide" for the medical profession. Call for a copy.

Restaurants

When was the last time you were able to hear the name of the soup du jour? Dining out is usually a major challenge. If you have some useful hearing, start by asking for a table away from kitchen and fan noise and any amplifiers for music. I have a friend who restricts her dining to a list of restaurants with quiet corners. Explain to the waitperson that you may have difficulty speechreading and want him or her to write down information delivered orally, such as choices of soup, vegetables, salad dressings, and pies. Most waitpersons will be happy to comply, if for no other reason than to hope for a larger tip.

At the table, you may want to seat yourself so that you are in the middle of the group and can face as many

people as possible. If the candle or flowers block your view, re-locate them. If you can use an assistive listening device, it may help, particularly if you can pass the microphone around to the speaker. Otherwise, your conversation will probably be limited to your near neighbors... unless you learn sign language and are with a group of people who can sign.

Fast food drive-thru windows represent another barrier. Although some years ago, Burger King is supposed to have settled a suit brought by someone who disputed the accessibility of drive-thru intercoms for deaf people, there have been no changes in any of the chains I've seen, aside from a note about the availability of Braille menus. You can go inside to order, of course, but that would be a moral victory for the restaurant. The best approach would seem to be to place your order slowly and clearly, repeat it slowly and clearly, then tell The Voice at the other end, "That's it. I can't hear you and am moving up." If you're creative, you may be able to come up with something more original. And if you can't even hear the squawking of the intercom, you'd better be creative. A few years ago, **ALDA News** editor David Coco described how he used the amplifier of the order station as a tactile aid at a drive-in hamburger joint in Texas. "A well-trained finger [placed on the speaker to sense vibrations] can easily distinguish between a hamburger, which is *buhbuhbuh* and a double cheeseburger, which is *buhbuh buhbuhbuh*. If you have any doubts about your "finger reading" ability, however, just repeat your whole order twice and cross your fingers. When you are fairly confident that he has your order straight, you say, 'Yes, that's all,' and then he tells you how much you owe. I generally skip this part and look for a twenty dollar bill since it is a bit difficult to finger read *two dollars and fifty-seven cents*, especially with a Texas accent." Update: Look for monitors, or LED Displays at fast food ordering stations - they display your order, price, quantity and total before you get to the window to pay.

■ Parties

One way to handle a social gathering is to arrive early so that you can chat privately with your host and hostess before the other guests arrive. During the party, try to find a quiet spot where you can position the speaker to best advantage. Or, if possible, you may be able to go into a quiet room away from the noise of the main room.

■ Driving and Traveling

Traveling presents an interesting set of problems. In case you were wondering, deaf drivers as a group have an impressive safety record.

- **In the car:** Conversing with a passenger while driving isn't really recommended. You need to concentrate on the road, and the tendency is to turn toward the speaker so you can speechread. This seems to upset passengers. I've had good luck using an ALD system in the car, but I sacrifice whatever small ability I have to hear sirens and ask my passenger to alert me to approaching emergency vehicles. The major American car manufacturers offer generous rebates on devices that warn of the approach of a siren. Turn signal audible/visual blinkers, wide angle rearview mirrors and overhead lights are practical too.
- **Air travel:** All of us know the story about the stewardess who gave a deaf passenger a card with Braille instructions. It usually isn't that bad. Until the airlines install monitors that tell travelers if flights are delayed or cancelled, the best approach is to arrive early and notify the ticket taker that you're deaf and that someone should personally deliver any announcements that come over the loudspeaker. Aboard the plane, the stewardess should again be reminded. Air travel is one area where universal design would be a real benefit for everyone.

- **UPDATE:** There is a product developed as an assistive listening device for use on an airplane. Some emergency videos are open captioned and it is advisable to confirm the destination when boarding.
- **Hotels and motels:** Under the ADA (see the second part of this chapter), places of public accommodation are required to provide communication access to deaf and hard of hearing people. This means that you should be able to arrange for closed captioned televisions, visual smoke and fire alarms, TTYs, telephone amplifiers, alarm clocks and door knocks. Call ahead to reserve the equipment, make sure it's there, and raise the dickens if it isn't. It's important for hotel management to know that this is not a trifling matter. Too often, people think that *accessible* is synonymous with wheelchair ramps. If there are conference rooms and meeting spaces, tell management about ALDS, CART, Interpreters etc.

■ Churches and Meetings

Places of worship do not fall under ADA regulations, unless they are used for public meetings. But most churches and synagogues are very responsive to their congregation's needs. The point, after all, is for as many people as possible to participate in the service. This is one area where you can have an impact. You can teach the church about available assistive listening systems, perhaps help try them out. You may be able to persuade people to donate money to buy the systems or you might volunteer to distribute receivers at services, or check batteries periodically. The MCDHH maintains a list of churches and synagogues which have interpreted services.

If you're concerned about the accessibility of meetings, phone ahead and speak to an organizer. Many have no idea that there are such things as CART service, interpreters, or ALDS. Dr. Michael Harvey tells of an incident many

years ago during the early days of assistive listening devices, when he was the very new director of DEAF, Inc., and the director of the Boston Guild for the Hard of Hearing called to find out if there would be ALDS at a conference DEAF, Inc. was holding. "Do we have them? Of course we have ALDS," Harvey assured the caller. After hanging up the phone, Harvey says, "I asked a colleague of mine, what is an ALDS?" So you can be an advocate in this type of situation as well.

For small meetings around a conference table, you should try a number of tactics:

- Ask for CART or CAN, or sit next to whoever is taking notes for the minutes and read over his or her shoulder.
- Ask for an interpreter/transliterators of your choice (oral, ASL, Signed English).
- Ask for a written agenda.
- You may be able to rearrange furniture. A U-shaped or circular table is usually best.
- Suggest that the chairperson use a whiteboard to write important points.
- Use an ALD if it can help you.
- Ask associates to speak one at a time and to face you.
- Ask the chairperson to repeat questions from the floor.

School

Many of the tactics listed above will also work in a classroom setting. If you benefit from an assistive listening device, the teacher can wear a microphone and carry a pocket-size transmitter in a pocket. CART, interpreters,

and CAN are all possibilities. Some students have been successful asking their teachers for copies of the lesson outline. As we saw in Chapter 1, Annette Posell came to class super-prepared; while her fellow students were struggling to finish the required reading, she was reading every item on the reading list, required and suggested. Helen Fleming tells how her family bought her a small tape recorder and volunteered to transcribe tapes of lectures, only to discover that it was a great deal harder than they expected. Today, CART service is commonly used by late deafened and severely hard of hearing students in schools and colleges.

■ What are your rights under the ADA?

The Americans with Disabilities Act was signed into law on July 26, 1990. It protects people with disabilities, including those who are deaf and hard of hearing, from discrimination in employment, hiring, transportation, access to public and private facilities and services, and telecommunications. Employers and business owners are required to make “reasonable accommodations” unless that creates an “undue burden.” The ADA also amended the Communications Act of 1934 to require that each state provide 24 hour a day Telephone Relay Service for consumers with hearing loss and speech impairments.

The scope of the law is very broad, as is its definition of “disability.” It covers, among others:

- state and local departments and agencies
- restaurants
- hotels and motels
- museums, stadiums, and libraries
- theaters
- doctors’ offices

- “consultants” such as lawyers and accountants
- banks
- health clubs

It mandates that TTYs, ALDS, captioned television sets, visual alarms, CART and interpreter services be provided in many circumstances and situations. Many businesses are slow to implement the ADA. If you think that a company is violating the ADA, for example, a movie theater does not provide ALDS, speak first with the management. Write letters. This is another area where consumers have a very strong voice because they can vote with their feet

For more information:

- **The Americans With Disabilities Act (ADA): Selected Resources for Deaf and Hard of Hearing People** (The Clerc Center #056)
- **Communication Access for Persons with Hearing Loss: Compliance with the ADA** by Mark Ross, Ph.D. (York Press, Inc.)
- **The Guide for Deaf and Hard of Hearing People**, National Center for Law and Deafness
- **People with Hearing Loss and the Workplace: A Guide for Employers to Comply with the Americans with Disabilities Act** (SHHH)
- Call MCDHH or a DHILS Program.

Other Important Laws:

Section 504 of the Rehabilitation Act of 1993 states that “No otherwise qualified handicapped individual in the United States..., Shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits

of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

The Individuals with Disabilities Education Act (IDEA) states, that ...“the purpose of this Act is to insure that all children with disabilities have available to them... a free and appropriate public education which emphasizes special education and related services designed to meet their unique needs, to assure that the rights of children with disabilities and their parents, or guardians are protected, to assist states and localities to provide for the education of all children with disabilities, and to assess and assure the effectiveness, of efforts to educate children with disabilities.

MCDHH offers an information sheet listing the ADA and other federal laws, as well as Massachusetts State laws and Executive Orders, related to the services and rights of people who are deaf or have a hearing loss.

Finale

■ Further Reading

There are a number of books on deafness that you may find interesting. The following sampling includes several written by late-deafened authors, as well as a handful of more generalized titles.

Claire Blatchford, **Full Face; A Correspondence About Becoming Deaf in Mid-Life** (Butte Publications, Inc., 1997). Available from the publisher at P.O. Box 1328, Hillsboro, OR 97123.

Richard Carmen, ed. **The Consumer Handbook on Hearing Loss and Hearing Aids: A Bridge to Healing**, SHHH, 1998

Marcia B. Duggan, **Keys to Living with Hearing Loss**, Barron's Educational Series: Keys to Retirement Planning, in collaboration with SHHH, 1997

Michael Harvey and Marylyn Howe, (ed.), **Psychological Effects of Acquired Deafness: A Training Outline**. Association of Late-Deafened Adults under a grant from the National Institute on Disability Rehabilitation and Research, 1996.

Shawn Lovely, **Now What? Life After Deaf** (Association of Late-Deafened Adults, 1996). Available from Shawn Lovely, 2812 Nomad Court West, Bowie, MD 20716.

Gayle McCullough, **What's Next?; What You Need to Know to Survive Sudden Deafness** (1994; available from *Life After Deafness*, 6773 Starboard Way, Sacramento, CA 95831)

Anne Pope, **Hear: Solutions, Skills, and Sources for Hard of Hearing People**, Dorling Kindersley in collaboration with SHHH, 1997

Susan Rezen and Carl Hausman, **Coping With Hearing Loss; A Guide for Adults and Their Families** (Barricade Books, Inc., 1993)

Bena Shuster, **Life After Deafness; A Resource Book for Late-Deafened Adults** (Canadian Hard of Hearing Assoc., 1995)

Elaine Suss, **When the Hearing Gets Hard** (Plenum Press, 1994)

Kay Thomsett and Eve Nickerson, **Missing Words; The Family Handbook of Adult Hearing Loss** (Gallaudet Univ. Press, 1993)

David Vernick and Constance Grzelka, **The Hearing Loss Handbook** (Consumer Reports Books, 1993)

■ Periodicals

- **Hearing Loss, the Journal of Self Help for Hard of Hearing People.** Bimonthly. Subscriptions available through membership only. SHHH, 7910 Woodmont Ave., Suite 1200, Bethesda, MD 20814
www.shhh.org
- **ALDA News.** Quarterly. Free with membership: ALDA, 10310 Main St., Box 274, Fairfax, VA 22030
www.ada.org
- **The Mike.** Free subscription with membership in Minuteman Implant Club, Inc. Larry Orloff, President, 209 Rolling Ridge Road, Amherst, MA 01002. Phone: (413) 549-4108 E-Mail: orloff@comcast.net
- **Contact.** Quarterly. Free with membership: Cochlear Implant Club International, www.cici.org
- **Hearing Health Magazine.** Deafness Research Foundation, 1050 17th Street NW, Suite 701, Washington, DC 20036. Phone: (202) 887-5850 (Voice); (888) 435-6104 (TTY); (202) 293-1865 (Fax)
www.hearinghealthmag.com

■ How to Order Material Mentioned in the Text

Some of the material mentioned in the “For more information sections” is followed by the name of the source in parentheses. Here is an explanation of these abbreviations:

- SHHH: can be ordered from the national office of Self Help for Hard of Hearing People. See address above. SHHH also carries a number of the books listed above.
- NTID: Request catalog from:

National Technical Institute for the Deaf Admissions
52 Lomb Memorial Drive
Rochester, NY 14623-5604
716/475-6700 (voice/TTY) www.ntid.rit.edu

- Laurent Clerc National Deaf Education Center
(The Clerc Center)

Publications and Information Dissemination
(age range Birth – 21 years) KDES – PAS6
Gallaudet University
800 Florida Ave. N.E., Washington, D.C.
202/651-5051 (TTY/voice)
202/651-5054 (fax)
E-Mail: Clearinghouse.InfoToGo@Gallaudet.edu
Ebsite: <http://ClercCenter.Gallaudet.edu/InfoToGo>

In Conclusion...

You've read the manual. It's now time to see if you can adopt any of the suggestions or want to pursue some of the them in-depth, time to discover what coincides best with your needs and personal style, what works for you. I hope I've been able to give you a groundwork on which you can build. Be adventurous. Have fun. Above all, maintain your sense of humor. The journey is just beginning.

If you have any suggestions, questions, or comments, I'd like to hear from you. I can be reached at:

KRockow@compuserve.com

Or contact:

The Massachusetts Commission
for the Deaf and Hard of Hearing
150 Mt. Vernon Street, Fifth Floor
Dorchester, MA 02125.

Bon voyage!

Credit for review and revision of the Fourth Edition also goes to:

April Spencer
Pamela Korzec
Jonathan O'Dell
Carole Rossick

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The Author ~

Karen Rockow began her professional writing career at the age of 13 as a columnist and sports reporter for the **Addison Independent** in Middlebury, Vermont. Her published work ranges from a survey of squash shoes to a study of funeral customs in the works of J.R.R. Tolkien. After receiving a doctorate in Folklore and Celtic Studies from Harvard University in 1982, she wrote software manuals for Spinnaker Software, SilverPlatter Information Service, and many other companies. She is a member of Self Help for Hard of Hearing People and the Association of Late-Deafened Adults, and serves on the consumer council of the Massachusetts Telephone Relay Service. She co-authored **Instant Access Guide to WordPerfect 5.0** and is now working on a resource guide for people with hearing loss.

The Agency ~

The Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH) is the central agency in state government in Massachusetts providing information, referral, public education, and many specialized services for Deaf, oral deaf, late-deafened and hard of hearing people. The MCDHH sought the development of this Guide in recognition of the need for earlier and better information about acquired hearing loss for individuals who lose their hearing, for the professionals who work with them, and for their family, friends and colleagues.

For information about obtaining more copies of this book or to access the services of MCDHH information sheets on the website contact:

Massachusetts Commission for the Deaf and Hard of Hearing
150 Mt. Vernon Street, Dorchester, MA 02125

617/740-1600 (voice) 617/740-1700 (TTY)

800/882-1155 (voice) 800/530-7570 (TTY)

www.mass.gov/mcdhh

e-mail MCDHH.Office@state.ma.us

